Disability Supports SERIES

Moving *in Unison* into Action:

Towards a Policy Strategy for Improving Access to Disability Supports

104-06080/

Moving In Unison Into Action:

Towards a Policy Strategy for Improving Access to Disability Supports

The Roeher Institute

Copyright © 2002 L'Institut Rocher Institute

All rights reserved. The use of any part of this publication reproduced, transmitted in any form or by any means, electronic, mechanical, photocopying, recording or otherwise, or stored in a retrieval system, without the prior consent of the publisher is an infringement of the copyright law.

National Library of Canada Cataloguing in Publication

Moving in unison into action: towards a policy strategy for improving access to disability supports / The Rocher Institute.
(Disability supports series)
Includes bibliographical references.

ISBN 1-896989-68-3

1. People with disabilities—Services for—Canada. 2. People with disabilities—Government policy—Canada. I. Rocher Institute II. Series.

HV1559.C3M68 2002 362.4'048'0971 C2002-901801-3

L'Institut Rocher Institute
Kinsmen Building, York University
4700 Keele Street
North York, Ontario, M3J 1P3
Tel.: (416) 661-9611
Fax: (416) 661-5701
TDD: (416) 661-2023

Institute President
Cameron Crawford

Project Coordinators
Cameron Crawford and Michael Bach

Lead Researchers and Authors
Cameron Crawford, Mary Anne Burke and Michael Bach

Other Researchers
Shawn Pegg
John Lord
Brian Salisbury
Steven Dowson
Orville Endicott

Design and Production
Is Five Communications

The recommended citation for this publication is:
Rocher Institute, Moving In Unison Into Action: Towards a Policy Strategy for Improving Access to Disability Supports.
North York, Ont.: L'Institut Rocher Institute, 2002.

The Rocher Institute gratefully acknowledges the financial contribution to this research from Human Resources Development Canada. The views expressed, conclusions drawn and any errors in the report are the responsibility of The Rocher Institute.

Contents

I **Introduction** 1

II **Defining Terms** 5

A. Disability 5

B. Disability Supports 5

C. Family 6

D. Transitions 7

E. Disability Supports Across Situations and Across the Lifespan 8

F. The "System" for Addressing the Need for Disability Supports 11

III. **Profiles of Key Players: People with Disabilities; Family Members; Specialised Community Services; and Generic Services, Programs and Opportunities at the Community Level** 13

A. People with Disabilities 13

1. Demographics of Persons with Disabilities 13

2. The Need of Persons for Disability Supports 16

B. Families of Persons with Disabilities 17

1. General Demographics of Families 17

2. Families' Needs for Support 18

C. The Community — Specialised Disability Supports and Services 20

D. The Community at Large — Generic Supports and Services 25

IV. **Key Policy Issues** 31

A. Introduction 31

B. Policy Issues for Persons with Disabilities 32

1. System for identification/assessment, planning and co-ordination of needed supports 34

2. Eligibility criteria 39

3. Access to personal disability supports — in-home, community, developmental, school and employment 45

4. Affordability of supports and services 47

5. Supports for persons with disabilities to live independently in the community 48

6. Summary of issues for persons with disabilities 50

C. Policy Issues For Families 52

1. Recognition and support for contributions families make to the disability supports system 52

2. Eligibility criteria 54

3. Adequacy of family supports — in-home, community and employment-related according to identified need 55

4. Cost to families 55

5. Cumulative impacts 59

D. Policy Issues For Communities 59

1. Inclusiveness of mainstream community services — recreation, school, workplace, health care, transportation, etc. 59

2. Accountability for full citizenship and inclusion by community sectors and governments 63

3. Investment in human resource development in the disability support sector, for training, education, wages and benefits, labour market development, collective bargaining arrangements 65

4. Strategy for the deinstitutionalisation of people with disabilities 68

V. **Context for Addressing the Policy Issues** 71

A. Federalism and the Social Union 72

B. Jurisprudence and Disability Supports 73

C. Community Supports and Service Delivery Context 74

D. International Policy Context 75

VI. **Summary and Future Directions** 81

VII. **Appendix** 85

A. Note on the use of the GSS 85

B. Tables 86

C. Discussion of Selected Trends 94

1. Jurisprudence On Disability Supports In Canada 94

VIII. **References** 101

Introduction

Disability directly touches more than one-fifth of the Canadian population. In 1991, there were 3.9 million children and adults with disabilities living in Canadian households (i.e., not in institutions — Statistics Canada, 1994 Table 1). Using the General Social Survey of 1996 The Roeher Institute has found that a further 2.6 million adults 15 years and older without disabilities were helping one or more people with everyday activities that year because of the receivers' long-term health conditions or disabilities. The help provided was largely informal, i.e., unpaid.

In their joint accord of *In Unison: A Canadian Approach to Disability Issues*, the federal, provincial and territorial governments committed to a new 'policy blueprint' for people with disabilities to achieve their full citizenship.[1]

Disability supports feature prominently in the *In Unison* report. *In Unison* advances the view that provision of disability supports in Canada should be strengthened through: a guiding vision of the full citizenship of people with disabilities and improved access, enhanced portability, more consumer control and greater responsiveness to individual needs.

The issue of disability support is a major area of concern expressed by the Council of Canadians with Disabilities in a recent position paper widely endorsed by the disability community.[2] Further, the need for and availability of disability supports have also been identified as major issues of concern among community and other organisations consulted by HRDC in preparation for the design of future research projects on disability issues.[3]

The issue of disability supports has received attention for good reason. Health status and social and economic well being are closely related to people's capacity to make key life transitions (e.g., from day care to elementary school, from elementary to high school, from school to work). Disability supports are in many instances a necessary condition for people with disabilities to participate in a range of economic and social activities and for making a variety of life transitions. Lack of support specific to disability is for many people inseparable from social and economic exclusion — unemployment, poverty, and isolation.

The findings of this study shed light on the conditions that would advance the objectives outlined in *In Unison*. The research set out to identify key transitions that children and adults with disabilities, and their families, seek to make or that they undergo in any event. It explores how such transitions are affected by the presence and absence of disability supports, accounts for the difficulties experienced by persons and families in securing needed supports, and points towards a policy strategy to address those issues.

At the outset it must be said that issues of disability support do not encompass all or even most of the issues that are flagged for attention in *In Unison*. That accord recognises that the labour-market inclusion of people with disabilities and the adequacy of their incomes are further conditions without which it is difficult to talk about people with disabilities achieving or exercising citizenship in any meaningful sense.

There are major challenges on the employment and income-support fronts for people with disabilities. Only about one-half of people with disabilities have paid employment. Disproportionate numbers of people with disabilities are involved in income programs, which generally provide very low incomes and in many instances present significant barriers to fuller participation in the paid labour force. Many of these challenges are widely understood within the disability community and are well documented.

As employment and income-support issues for people with disabilities require considerable attention in their own right, these areas lay beyond the scope of the present research. However, where issues of support for disability-specific needs are encountered by people seeking to participate in the paid labour force, or to further their education and job skills, those issues are examined.

In drilling in more specifically on the supports that people with disabilities need to carry on with their lives across a range of situations, the present research has drawn upon:

- Ten focus groups conducted by The Roeher Institute on issues of disability supports and life transitions for children and adults with disabilities. These sessions were conducted in Vancouver, Calgary, Toronto, Montreal and Halifax. The sessions involved approximately 150 people comprising: persons with disabilities; family members; disability advocates; government officials from provincial departments responsible for health, educational and social services; and a range of providers of direct service to people with disabilities (e.g., physicians, early intervention specialists, educators; managers/CEOs'of service-providing organisations.
- Key informant interviews with senior government officials in ministries of health and social services responsible for issues of disability and the provision of disability supports.
- A review of literature and analysis of trends and emerging issues around the delivery of services to persons with disabilities, conducted by John Lord.
- A review of Canadian case law on issues of disability supports, conducted by Orville Endicott.
- A comparative review of international initiatives in disability policy, conducted by Brian Salisbury and Steven Dowson.

To probe the magnitude of the issues raised in the focus groups, interviews and other data sources, the report has also drawn from primary statistical data sources that include micro-data (i.e., raw data) and published tabular data from:

- The Health and Activity Limitation Survey (HALS) of 1991;
- The National Population Health Survey (NPHS) of 1996-97. Owing to the relatively small sub-sample of people with disabilities in the 1998 survey, the research generally did not to use that source, as some of the analysis would have relied upon sample sizes too small for unqualified and even qualified release.
- The National Longitudinal Survey of Children and Youth (NLSCY 1998 edition for 1995-95 reference years)
- The Survey of Labour and Income Dynamics (SLID Longitudinal file for 1993-94).
- The General Social Survey on Community and Social Support (GSS Cycle 11, 1996).

With the exception of HALS, these surveys do not cover people living in the northern territories. None of the surveys include people living on First Nations Reserves or barracks on Canadian Armed Forces bases. While HALS and the NPHS have separate surveys of people living in health-related institutions, those institutional surveys were not consulted as the focus of the research is on people living in the community.

The acronyms HALS, NPHS, SLID, NLSCY and GSS are used throughout this report.

Chapter II defines terms that are used frequently in the report. Chapter III provides brief profiles of people with disabilities, their families, specialised services and generic programs and opportunities at the community level. Chapter IV focuses on key policy issues facing individuals, families, specialised services and communities more broadly. Chapter V provides an overview of the context for addressing policy issues — federalism and the social union, jurisprudence on disability supports, the service delivery context and international policy developments. Chapter VI provides a summary of key findings and suggested future directions for efforts to address the issues raised in this research. The Appendix provides notes on statistical sources, tables not included in the body of the report and a fuller discussion of the jurisprudence and service delivery context for addressing issues.

Cameron Crawford and Michael Bach directed the research for this project and, with Mary Anne Burke, wrote the report. Shawn Pegg conducted background research and prepared summaries on selected themes.

---

1 *In Unison* is an accord of the federal-provincial/territorial governments. Quebec has stated support for the intent of the accord but is not a formal signatory.

2 Council of Canadians with Disabilities (November 1999). A National Strategy For Persons With Disabilities: The Community Definition.

3 "Findings from Consultations on the Health and Activity Limitation Survey 2001", Ottawa: Applied Research Branch, Income Security and Social Development, HRDC, January 14, 2000.

II

Defining Terms

A. Disability

We define disability as limitations in carrying out activities of daily living and to participating in the social, economic, political and cultural life of the community. Such limitations may arise from:

- a physical, sensory, intellectual, emotional or other personal condition such as a long term health problem;
- societal stereotypes about such human conditions, or
- ways of organising social, economic and built environments that, in their effects, exclude or impede the participation people with such conditions.

B. Disability Supports

To make key life transitions and to carry on with life more generally, many people with disabilities need one or more supports specifically because they have a disability. We define a disability support as any good, service or environmental adaptation that assists persons with disabilities to overcome limitations in carrying out activities of daily living and in participating in the social, economic, political and cultural life of the community.

Disability supports needed to address such factors would typically include:

- Personal help for everyday activities (e.g., for meal preparation; shopping for groceries or other necessities; normal housework; heavy household chores; personal finances, such as banking or paying bills; personal care such as washing grooming, dressing and eating; and help moving about at home). Such help may be provided informally by family, friends and neighbours, or formally through non-profit, for-profit or government agencies.

- Personal planning supports for persons with disabilities and their families such as: needs identification, personal and transition planning, service co-ordination, etc.
- Aids and devices or specialised services needed by persons across a range of situations to address issues of hearing, speaking, seeing, mobility and agility (e.g., hearing aids, oral interpreters or sign language interpreters, voice synthesised computers, wheelchairs, prosthetic hands or arms)
- Personal help, specialised services, modified physical environments or aids and devices needed for school, employment, recreation or other specific situations
- Specialised features to enter or leave the personal home environment such as ramps, street level entrances, widened doorways or hallways, elevators or lift devices, accessible parking or passenger zones, lever door handles, Braille characters, voice message systems and various other measures
- Features within the home setting such as grab bars, elevators or lift devices, widened doorways or hallways, visual or flashing alarms, audio warning devices, automatic or easy to open doors, lowered counters or sinks, lowered switches, lifts for beds or baths, emergency call systems and various other features
- Medications (e.g., for psychiatric and neurological conditions, pain management, chronic heart or other condition)
- Various developmental/therapeutic services (e.g., physiotherapy, occupational therapy, audiology, speech therapy, vision services, personal, school, career and psychological counselling)
- Transportation supports specific to disability and under the direct control of persons with disabilities (e.g., modified personal vehicles)
- Family supports such as caregiver relief (respite service) on a short-term or emergency basis for family members who provide support to people with disabilities, family counselling and employment leave benefits for care giving

Support is also available through broad measures at the community level that benefit people with disabilities as a group. Such support would include:

- Accessible community infrastructure (e.g., accessible buildings, sidewalks, transportation services and public technologies such as computers at schools or libraries); and
- Human capacity at the community level to fully include people with disabilities in regular community activities (e.g., child care workers and teachers able to respond to the needs of children with disabilities in regular child care, school or recreational settings).

C. Family

It is understood that the Canadian family has undergone many changes in recent years and that notions of what and who constitutes a family have shifted as well. Statistical tools used in this research presented certain limitations. The term "family" as used in the statistical analysis means spouses/partners, ex-spouses/ex-partners, sons/daughters, grandsons/granddaughters, grandparents, in-laws, cousins, nieces/nephews and uncles/aunts.

D. Transitions

In a series of roundtables held across the country by The Roeher Institute for this research, people with disabilities, their families, and professionals working in the field identified many transition points in the lives of people with disabilities and their families. A transition is defined simply as a change or passage from one place, state, act or set of circumstances to another.

Respondents in all focus groups agreed that inadequate supports and services compound the turmoil around the various transition points, resulting in higher levels of stress than necessary. They also identified the tendency for systems of supports and services to break down around times of transition — especially when transitions involve shifts within and among systems, such as transitions from high school to post-secondary education or to work.

Respondents identified transitions that reflected and were specific to particular ages and to life-stage changes and others that were experienced at all ages and stages of life. They suggested actions that could be taken at the level of persons, families and communities to better support people with disabilities and their families through these transitions. The various transition points identified — whether in childhood, adolescence or adulthood — can be grouped into three broad categories:

1) Personal disability-related, including transitions from:

- Diagnostic interventions to recognition of disability
- A known set of abilities to new ones, for example because of changes in the nature and degree of the disability such as in the case of a degenerative condition
- A highly medicalised and medicated state to a de-medicalised and de-medicated state
- From having a disability to not having a disability; from not having a disability to having a disability

2) Family and living situations, including transitions from:

- Family care into day care, respite care or out-of-home care
- Institution (including health care and treatment facilities) to home in the community (and sometimes back to institutional care)
- Familiar routines due to the birth, death, marriage, divorce, change of job or retirement of family members, care providers or teachers
- Youth to adulthood and to the new expenses and responsibilities that come with adulthood
- Reliance on parental support to reliance on other supports, if on any at all
- A highly managed situation to greater independence and autonomy
- Familiar to new housing and communities
- A familiar culture/language to new ones because of immigration
- Home to home
- Community to community
- Province to province

- Ministerial jurisdiction to jurisdiction (e.g., from education to community or health services or between and within school systems)

3) Community involvement, including transitions from:

- Parental care to child care
- Child care to pre-school
- Pre-school to school
- Primary school to junior high school
- Junior high to senior high school
- High School to post-secondary education,
- Segregated school settings to inclusive settings, or vice versa
- School to life in the community, including social and recreational activities
- School to work
- School to an absence of stimulating daytime activity
- Job to job
- Work to retirement

Other transitions were identified, but were not a major focus of attention. These included the transition into parenthood, the transitions experienced through grieving the loss of family and friends, the transition into "offender" status (especially for youth with foetal alcohol syndrome), the transition to comparative wealth (e.g., upon receiving an inheritance) and the transition to "committeeship" or guardianship.

E. Disability Supports Across Situations and Across the Lifespan

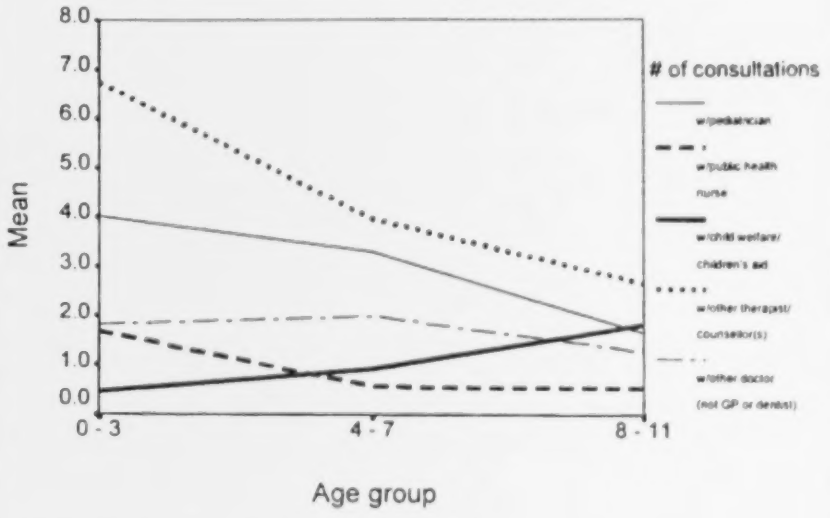
Needs for disability supports may vary considerably across life situations — across the transitions that people make. For example, supports needed by the child at school (e.g., note taking, tutorial or other forms of personalised assistance) are usually not the same as those needed at home, although some of those supports (e.g., help with personal care) may be required both at school and at home. The adolescent or adult who plays wheelchair basketball likely needs a different wheelchair for that sport compared with the wheelchair needed at school or at work.

Furthermore, people may need different supports at various stages in the lifespan (**Figures 1 - 3**). For example, young children injured in a car accident may require speech therapy and physiotherapy in their pre-school and school years, but not later in adulthood. The person with cerebral palsy may need more intensive assistance from a physiotherapist as he or she gets older. The wheelchair or leg braces needed by a child are not the same wheel chair or braces needed by the adolescent or fully-grown adult. Nor is the attendant who is effective with a school-aged child necessarily the person with the skills needed to support that person who has matured to become a business executive.

While the form of a given support may need to be different at various points in the lifespan, many persons will need some form of that support on an ongoing basis. For instance, the child rendered quadriplegic in a car accident and who needs a wheelchair will likely need some kind of wheelchair as an adolescent, as a working-age adult and as a senior citizen. The young person with Down Syndrome who needs additional help learning at nursery and elementary school, may require such assistance geared to age and intellectual development throughout high school, at home and at work as an adult, and in retirement.

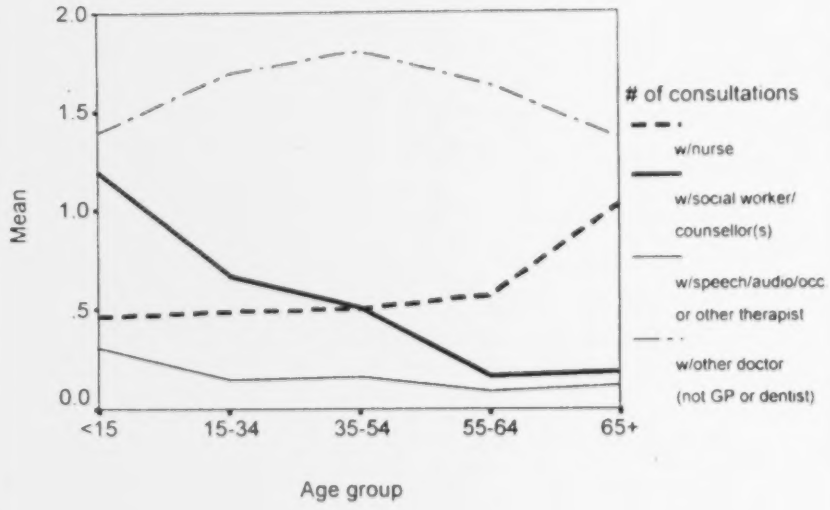
Figure 1 shows the generally decreasing contact between children with disabilities and pediatricians and public health nurses through the school years. However, contact with child welfare / children's aid counsellors increases though the school years. **Figure 2** shows that the contact between people with disabilities and various counsellors and social workers tends to decrease after school leaving, while contact with nurses tends to increase. Contact with various doctors (aside from general practitioners and dentists) tends to be highest in middle adulthood.

Figure 1. Number of consultations between children with disabilities and selected professionals



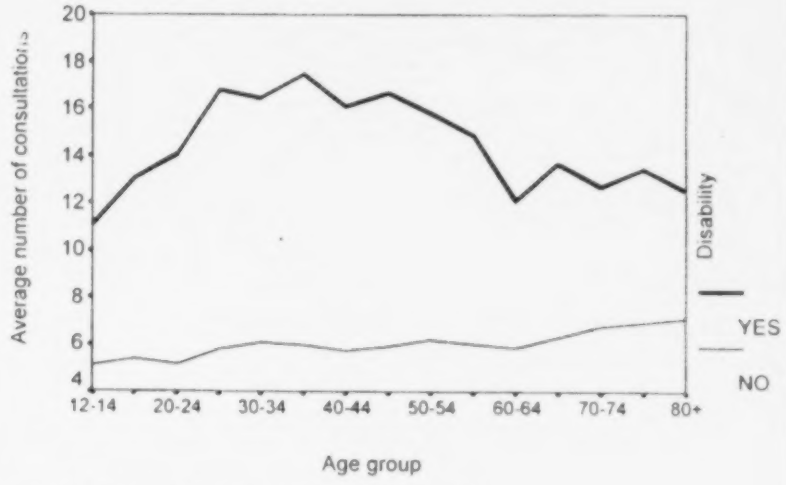
Source: The Roeher Institute based on NLSCY 1996

Figure 2. Number of consultations between people with disabilities and selected professionals



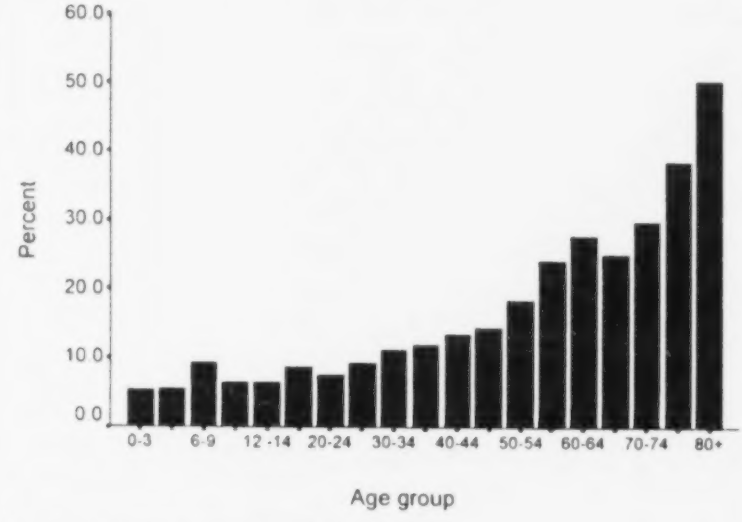
Source: The Roeher Institute based on NPHS 1996-97

Figure 3. Average number of health-related consultations, by age group and disability



Source: The Roeher Institute based on NPHS 1996-97

Figure 4. Prevalence of disability by age group



Source: The Roeher Institute based on HALS 1991

Most people, however, acquire a disability not at birth or in early childhood, but sometime after completing their formal education; the prevalence of disability increases in a fairly stable curvilinear fashion with the advance of age (**Figure 4**). If the need for disability supports has elements of constancy and change across the lifespan for people with disabilities acquired early in life, the need for any disability support comes as something new for most people.

Once disability supports are needed, however, the same general rules apply. Supports needed in some years and situations may not be needed in others. Some supports may be needed across situations and in all years, although the form of those supports will likely need to be attenuated to various circumstances.

F. The "System" for Addressing the Need for Disability Supports

A complex "system" has evolved piecemeal in Canada for responding to the need for disability-supports. It consists of:

- **People with disabilities**, who often identify their own needs and the supports required to meet those needs, and who in many cases personally make necessary arrangements to secure and direct/manage those supports. As well, people with disabilities (502,000 people based on the GSS of 1996) are in many cases the providers of assistance to others on account of others' long-term health conditions or disabilities.
- **Family members**, who often assist persons with disabilities to identify their needs and required supports, and who often directly provide the required support (e.g., help with everyday activities; assistance in securing services or aids and devices from community agencies; help with medications and with the use of medical equipment). These informal care providers, supported by friends and neighbours, form the backbone of the disability support system.
- **Specialised organisations in the community with a focus on providing goods and services to persons with disabilities.** Such organisations also support and back up informal care providers, and include:
  - charitable foundations that may provide assistive devices, home modifications or vehicle retrofits at little or no cost to persons;
  - for-profit and non-profit organisations that provide a wide range of services such as homemaker and nursing services, supports for independent living, support for community access and participation, sign language interpretation services, service planning and co-ordination, Braille instruction, and various therapies (e.g., occupational, speech and physiotherapy);
  - government and quasi-government organisations (e.g., Workers' Compensation programs, provincial vocational rehabilitation programs) that may directly deliver various goods and services to persons with disabilities.
- **Generic community institutions**, services and programs that make provision to include and support persons with disabilities and their families and other informal care providers. Such generic institutions, services and programs include nurseries and day care centres, schools, libraries, municipal parks and recreation centres, hospitals and other health care services, public transportation services and employers who may ensure the availability of personal assistance, aids/devices or other job accommodations in the workplace.

A complex set of tensions, trade-offs and ultimately choices govern interactions within this system. For instance, where a school is fully inclusive of a child with a disability, there is less need for family members to make private payments and other arrangements to bring learning technologies (e.g., modified computer) and other supports (e.g., attendant) into the school. Where the school makes provision to accommodate one child, it may as a result have the capacity to accommodate other children as well, achieving economies of scale in the process. In contrast, where the school makes no provision to accommodate a child, the full weight of responsibility and cost falls to the family. The responsibility and costs may not be supportable, driving the family to seek income and specialised services from the province's

ministries of health and children's services. Several children who would otherwise have been at the exclusive school, funded under the ministry of education, may be in a similar position, which results in duplication of the demand for — and costs of — "special" supports across families and from across ministries. This may ultimately result in greater public expense in the long run (e.g., three computers and three attendants for three children at home rather than one computer and one attendant for three children at school, who do not all need the computer or the attendant at the same time).

Similarly, society may have decided that the family is primarily responsible for meeting the needs of the man who becomes disabled as a result of an accident at home. His spouse/partner may be consigned to playing a major role in providing support. In the near term this may seem cost-effective from society's point of view. However, after several years, his spouse may begin developing health problems, which results in more frequent visits to doctors and overnight stays in hospital. Because she did not have access to occasional respite, and because her responsibilities have taken a toll on her health, she now needs occasional nursing support at home. She may have altogether left what was previously a full-time job, resulting in lower household income for the family and lower tax revenue for governments.

Where community recreation programs and social clubs take measures to ensure that their premises and activities are fully accessible to people with various functional limitations, there is less need for those individuals to secure their own attendants on a person-by-person basis to help them participate in the community. In other words, where generic programs ensure accessibility and adequate support, there is less need for specialised and usually more costly services to step into the breach.

Where employers, perhaps with back-up support from the federal or provincial government, ensure that job tasks and routines are suited to individual capacity, and that adequate technological, human and procedural support is available in the workplace, there is likely to be less unemployment and economic marginalisation of people with disabilities. In turn there will be less demand on income support programs, better mental health and lesser demand for mental health services, and lesser demand for specialised services (e.g., home care) to assist at home throughout the day when the person would otherwise be working.

These examples show that disability support "system" involves highly interdependent players. Where and how investments are made in any one component of the system can affect the demands upon other components, and can affect the capacity of the system overall to adequately support individuals. Some investments may result in greater overall effectiveness than others in achieving valued outcomes for individuals, families and communities at large. Some choices about where, why and how to invest can result in overall ineffectiveness and hardship for individuals, families and communities.

III

Profiles of Key Players:
People with Disabilities; Family Members; Specialised Community Services; and Generic Services, Programs and Opportunities at the Community Level

A. People with Disabilities

1. Demographics of Persons with Disabilities

The following facts and figures about persons with disabilities are drawn mainly from a recent report produced by the Federal, Provincial and Territorial Ministers Responsible for Social Services (2000):

Basic Demographics

- In 1991, 16 per cent of Canadians had a disability. Of these 4.2 million people, 3.9 million were living in the community and a further 273,000 in institutions.
- 56 per cent of people with disabilities were of working age (15 - 64 years); 9 per cent were children 14 years and younger and 35 per cent were people 65 and older.
- Slightly more than half of adults living with a disability were affected by a mild disability. One third were considered to have a moderate disability and 14 per cent a severe level of disability.
- The Aboriginal Peoples Survey of 1991 revealed that 31 per cent of Aboriginal adults reported some form of disability, nearly twice the national average.
- The disability rate among young adults was nearly three times higher for Aboriginal people than for non-Aboriginal people.
- Among Aboriginal adults 66 per cent were affected by a mild level of disability, 22 per cent by a moderate disability and 12 per cent by a severe level of disability.
- The likelihood of having disability increases with age. As the population ages, the incidence of disability is increasing.

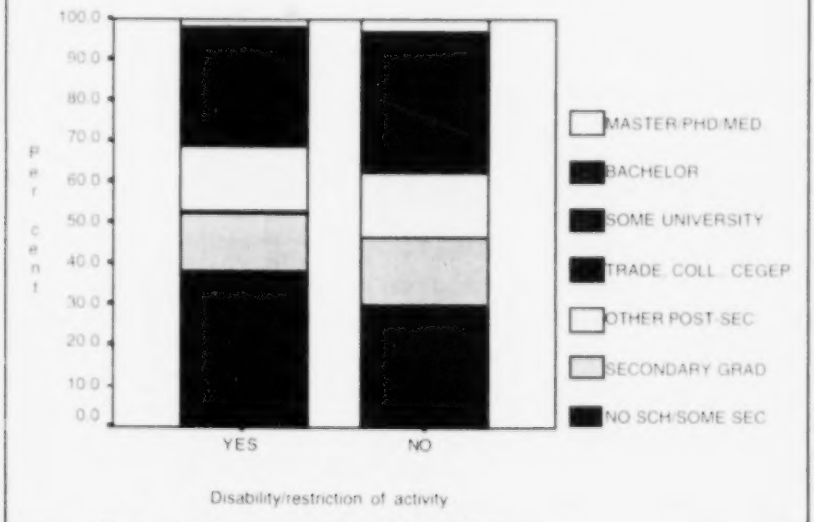
Employment

- In 1995, 43 per cent of working age people with disabilities were participating in the paid labour market — about half the percentage of people without disabilities.
- 14 per cent of women with disabilities worked for pay full-time for the full year; 62 per cent did not work for pay at any point in the year.
- More than half of men with disabilities were without paid employment for the full year compared to less than ten per cent of men without disabilities.
- In 1995, the unemployment rate of persons with disabilities was 16 per cent, compared with 9 per cent for persons without disabilities.
- The unemployment rate was highest among young Aboriginal men aged 15 to 34 with disabilities, at 34 per cent.
- Between 1990 and 1995, there was a decrease in full-time, full-year paid employment. For people with disabilities, this resulted in the loss of paid work for many people, particularly men.

Income

- In 1997, working-age adults with disabilities were nearly twice as likely as adults without disabilities to be living on low income. Some 26 per cent of adults with disabilities were living below the low-income cut-off, compared with 11 per cent of people without disabilities.
- The depth of low income is greater for people with disabilities: 17 per cent of adults with disabilities have incomes more than 25 per cent below the low-income cut-off, compared with 6 per cent of those without disabilities.
- Working-age men with disabilities were more than six times more likely than men without disabilities to rely on government income support; women with disabilities were nearly three times as likely as women without disabilities.
- Men with disabilities were only half as likely as men without disabilities to rely on earnings as their largest source of income.

Figure 5. Highest education of persons 12+ with and without disabilities



Source: The Roeher Institute based on NPHS 1996/97

Education

The Roeher Institute's analysis of the National Population Health Survey has found that the education level of people with disabilities is lower than their counterparts without disabilities (**Figure 5**).

Movement Into and Out of Disability

Research by The Roeher Institute (1998) has also found considerable movement into and out of disability status. For example, based on SLID data for 1993 and 1994 it was found that:

- A significant share of people who reported disability in one year (28 per cent) did not report disability in the following year.
- A significant share (23 per cent) who did not report disability in a given year did report a disability in the following year. (**Table 1**).
- Women were more likely than men to report disability in only one of two concurrent years.

Having said this, a significant share of people (nearly half) reported disability across both years.

- The level of paid employment among these people (of working age) was very low — only 22.1 per cent were employed consistently throughout 1993, a figure that dropped to 18.9 per cent in 1994.
- They were about twice as likely as people without disabilities in either year to have less than high school graduation. In contrast, those who reported disability in only one year were about one and one-half times as likely as people who did not report disability in either year to have less than high school graduation.
- They had considerably lower incomes than others. In 1994, 28.4 per cent of working-age people with disabilities in both years were living below the after tax low-income cut-off, compared with only 10.2 per cent of people without disabilities in either year. Some 14.3 per cent had incomes more than 25 per cent below the low income cut-off (after taxes), compared with only 5.6 per cent without disabilities in either year.

Table 1. Working-age persons with and without disabilities, showing sex and disability status (SLID)

DISABILITY STATUS					
	No disability either year	**Disability 1993 only**	**Disability 1994 only**	**Disability both years**	**Total**
Total number of valid responses across both years	14,665,000	773,000	651,000	1,367,000	17,455,000
SHOWING PERCENTAGES OF TOTAL RESPONDENTS					
Per cent of valid responses for disability across both years		27.7%	23.3%	49.0%	100.0%
SEX					
Male	48.8%	43.8%	42.9%	49.8%	48.4%
Female	51.2%	56.2%	57.1%	50.2%	51.6%
Total	100.0%	100.0%	100.0%	100.0%	100.0%

2. The Need of Persons for Disability Supports

Unpublished research conducted by The Roeher Institute has found that the extent of persons' need for disability supports is considerable. For instance:

- About two million adults with disabilities need help with one or more everyday activities because of disability (1.9 million in 1991 based on HALS; 2.3 million in 1996 based on the NPHS).
- Data are scarce on human supports used by children with disabilities. However, it is known that, among the 104,000 children with disabilities in special education schools or special education or remedial classes in regular schools, 43,000 receive physiotherapy, occupational or communication therapy. Another 22,000 receive daily living skills training.
- More than one million adults need aids / devices to address issues of seeing, hearing, speaking, movement or the use of hands and arms.
- Some 69,000 children with disabilities use one or more such devices.
- Nearly a quarter million adults with disabilities (219,000 people) need modified features to enter or leave their homes; 254,000 people need special features within the home. In total, 397,000 need home modifications. Not everyone needs both internal and external features.
- **Appendix Table 7** shows the numbers of children with disabilities who use various modified features of the home environment.
- Nearly 35,000 working age students with disabilities needed personal services or technologies in order to attend classes in 1991. There is a considerable need among students with disabilities for personal services such as note takers, scribes, readers, tutors and attendants. Computer access was the most widely required technological support at the time HALS was conducted.
- 37.1 per cent of working age people with disabilities, or 728,000 people, need one or more architectural, technological, human or work-routine accommodations for work. The most widely needed job supports are modified hours and job redesign. A significant proportion of people need modified architectural features and ergonomic measures in the workplace (12.0 per cent) (**Table 24**).
- 42,000 children with disabilities received specialised assistance at school, such as attendant care, readers, note takers or scribes in 1991.
- More than 370,000 adults with disabilities (10.5 per cent) had difficulty with local transportation arrangements in 1991 because of disability. Some 200,000 drivers or passengers with disabilities (5.7 per cent) used modified features for private vehicles because of disability in 1991.
- 23,000 children with disabilities used specialised van or bus service to travel to school. 12,000 children with disabilities use specialised van services more generally in the community almost every day for some part of the year, frequently or occasionally.
- More than 2 million adults with disabilities regularly take medications because of their condition. It is unknown how many children with disabilities regularly take medications, although non-reimbursed expenses for prescription and non-prescription drugs were incurred for 79,000 children because of disability in 1991.

B. Families of Persons with Disabilities

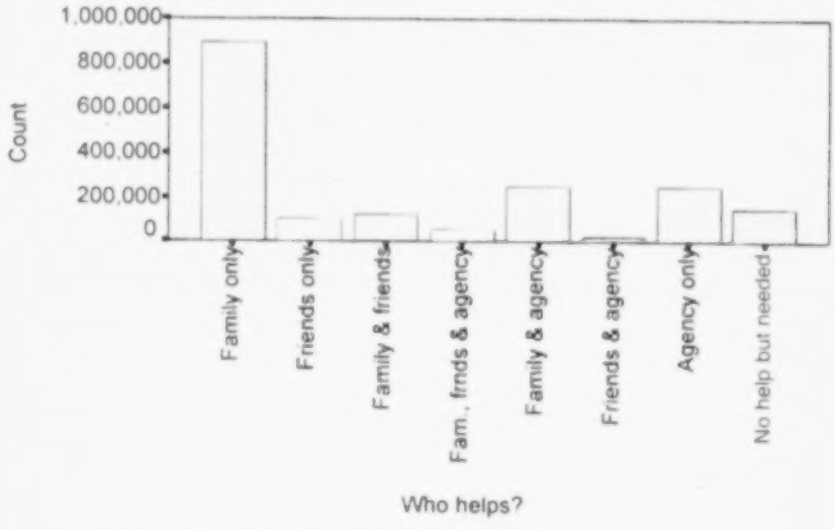
1. General Demographics of Families

Family members are extensively involved in providing direct support to people with disabilities. Based on HALS 1991, The Institute found that family members, without help from friends or service agencies, responded to the disability-related needs of 49 per cent of — or about 900,000 — people who require such support. Family members are involved in a further 23 per cent of cases (i.e., they help a further 418,000 people) with additional assistance from the friends of those helped or from community service agencies (**Figure 6**).

Most people who provide help to family members because of disability are women (60.5 per cent based on the GSS).

Most of the family members who provide help on account of disability are younger than 45 years of age (**Table 2**). The estimated average age of family members who provide help in everyday activities because of disability is 45 years, compared with 44.4 years among people who do not provide help because of others' disabilities.

Figure 6. Number of adults with disabilities helped by family, friends, and/or community agencies



Source: The Roeher Institute based on HALS 1991

Table 2. GSS respondents giving/not giving help to family members because of family members' disabilities

Age group	Do not help because of disability		Help because of disability	
15-24	3,616,000	17.8%	245,000	10.9%
25-34	4,224,000	20.8%	397,000	17.6%
35-44	4,159,000	20.4%	604,000	26.8%
45-54	3,122,000	15.3%	560,000	24.9%
55-64	2,129,000	10.5%	245,000	10.9%
65-74	1,865,000	9.2%	146,000	6.6%
75-84	997,000	4.9%	49,000	2.2%
85+ **	229,000	1.1%		-
Total	**20,341,000**	**100.0%**	**2,253,000**	**100.0%**

** The number of people 85+ who provide help because of roster members' disabilities is too small to report.

The research found that those helped because of disability are mainly parents (44.3 per cent), followed next by spouses/partners (30.3 per cent). Sons/daughters and siblings form a significant but less sizeable proportion (16.7 per cent in total). Grandparents are next (5.4 per cent), followed by uncles, aunts, cousins and nephews (3.3 per cent). The number of Canadians helping grandchildren because of the grandchildren's disabilities is too low to report (**Appendix Table 9**).[1]

In many instances, family members who provide help live in the same household, building or neighbourhood as the people who receive help (i.e., in 71.4 per cent of cases). In many other instances, family members who provide help live in an adjacent community (17 per cent of cases). In a significant number of further cases (11.6 per cent), those who help other family members live a considerable distance away (i.e., several hours or more) from those who receive help.[2]

Overall, 9.5 per cent of the adult population in Canada (aged 15 and older) provide help to family members because of disability. The per centage of family members who provide help is higher than the national average in New Brunswick (10.8 per cent), Nova Scotia (18.4 per cent), Prince Edward Island (22.5 per cent), Newfoundland/Labrador (17.5 per cent) and Manitoba (10.9 per cent).

2. Families' Needs for Support

On average, people who help family members in everyday activities because of disability invest 316 hours per year in providing the assistance, or the equivalent of 40 eight-hour workdays. Some 144,000 family members who provide help with everyday tasks because of disability invest 20 hours per week or more in this work.

Some 959,000 family members who provide help because of disability consider themselves to be the primary caregivers of those helped. Generally, those who

Table 3. Proportion and number of people providing help to family members due to disability, who expect to continue providing assistance, by activity where assistance is provided

	Family members providing help	Family members who expect to continue providing help	Per cent who expect to continue providing help
Child care	—	—	—
Meal preparation	858,000	671,000	78.2%
House cleaning	746,000	578,000	77.5%
Home maintenance	629,000	559,000	88.9%
Shopping	1,011,000	876,000	86.6%
Transportation	1,059,000	900,000	85.0%
Banking & bill paying	625,000	517,000	82.7%
Personal care	774,000	550,000	71.1%

provide care and support to family members because of disability expect to continue providing such help indefinitely (**Table 3**).[3]

More than half (54.3 per cent) of those who help family members because of disability indicate that, in order to continue providing help, it would be useful if they themselves had access to one or more supports. Such family supports include financial compensation, occasional relief, flexible work/study arrangements, information on how to be effective providers of care, information about the nature of family members' disabilities, counselling or various other measures.

In many cases, people who help a family member because of disability help more than one person (family and otherwise) who require disability-related assistance (in 62 per cent of cases where family members provide help because of disability, involving nearly 1.5 million family care providers).

As well, family members provide the following supports in addition to providing help with everyday activities because of disability

- Emotional support (708,000 family members)
- Checking up the general well-being of those helped due to disability (1,224,000)
- Help with the use of medical equipment or assistance with medications (506,000)
- Assistance socialising (729,000)
- Help to obtain information, make appointments or negotiate the provision of services (801,000 family members).

In 52.4 per cent of cases where family members indicate that they are the primary care givers for the persons helped due to disability, the family members do not receive help from others in the process. In 59.3 per cent of cases where family members are primary care givers, no one else steps in to provide help with every day tasks when the family members need to take a break.

C. The Community – Specialised Disability Supports and Services

To create a snapshot of employees who provide direct services to people with disabilities, the research consulted data from major surveys such as the Survey of Labour and Income Dynamics and the National Population Health Survey. However, these surveys do not provide enough detail about respondents' employment activities to yield the information sought.

Analysis of the 1996 GSS found that 295,0000 people were involved in providing disability-related help to others with everyday tasks through non-government organisations (NGOs). A further 130,000 were involved in this capacity through government agencies. Such activities included:

- Child care
- Meal preparation, housecleaning or house maintenance
- Grocery shopping, transportation, or banking/bill paying
- Personal care

People providing one or more of these supports through agencies in many instances also provided informal checking up, emotional support, help with the use of medical equipment or assistance with medication, assistance in socialising and obtaining information, making appointments and negotiating the provision of services.

The following discussion explores basic demographics of such workers. The analysis does not include people who provide other specialised services that people with disabilities need, such as various therapies, communication services (e.g., for people who are deaf, deafened or hard of hearing), counselling, assistance with disability-related technologies, and so on. Nor does the research focus on volunteers in NGOs, who are an important component of the human resources of those organizations.

Most of those who provided help with everyday activities through NGOs are classified as working in the "community services" sector (79.5 per cent), as opposed to public administration or other sectors of the economy. The same is true among those who helped through government organisations (85.8 per cent).

Most of the people who provided disability-related assistance were women — 69.3 per cent in NGOs and 76.5 per cent in government agencies.

The average age of those who provided help through NGOs was somewhere between 40 and 44 years, compared with 35 to 39 years among those who helped through government agencies.

Most working through NGOs were born in Canada (83 per cent) — roughly the same as in the Canadian population as a whole (80.3 per cent). An even higher proportion (90.7 per cent) of those helping through government agencies was born in Canada.

As with the general population, among whom 79.5 per cent live in urban communities, most who provide help through NGOs lived in urban communities (77 per cent). Of those who provided help through government agencies, 82.7 per cent resided in urban communities.

Most GSS respondents providing disability-related help through NGOs were working for pay as their main activity (65.1 per cent). This is considerably lower than the 72.9 per cent helping through government agencies. People helping in NGOs worked on average 32 hours per week for 47 weeks of the year, compared with 34 hours for 42 weeks among those who helped through government agencies.

The estimated personal income of those who helped through NGOs was $21,900 — lower than for the Canadian adult population as a whole ($26,000). The average income of people in government agencies helping with everyday tasks because of disability was $23,200.

The main source of household income for those helping through NGOs was employment earnings (for 79.1 per cent). This is higher than among the adult population as a whole (68.7 per cent) but considerably lower than among people who helped others through government agencies (90.1 per cent).

The estimated household or total family income for people helping through NGOs was considerably lower than for the general population ($41,900 compared with $47,600) and for those who helped through government agencies ($49,600).

When the GSS was conducted, a significant share of the adult population who were not providing help to others because of disability reported that their main activity was going to school (13 per cent). Similar figures for people who provided help through NGOs, or who were working with government agencies, are too small for release. However, analysis of GSS data found that people providing help through government agencies because of disability were nearly twice as likely as those in NGOs to report that going to school was their main activity. Those providing help because of disability through government agencies were nearly twice as likely as those in the NGO sector to be taking any courses towards certification (53.7 compared with 28.3 per cent).

The low participation in education among people helping through NGOs is somewhat surprising in that their education level is, on average, about the same as that for people helping through government agencies. Some 51.8 per cent had a post-secondary certificate, diploma or degree, compared with 49.6 per cent among those who provided help through government. In contrast, 38.6 per cent in the population as a whole had some form of post-secondary certification.

Concerning the employment impacts on those who provided help through the community service system, the research found split results. On the one hand, most (65.5 per cent or 275,000 people) reported that they nearly always feel that by helping others they are simply giving back some of what life has given in the first place. Most (69.7 per cent or 294,000 people) reported that they nearly always feel that helping others strengthens their relationships with the people helped.

On the other hand the analysis found issues and difficulties that require attention:

- While most providing help through NGOs (55.9 per cent) indicated that they do not need any information, counselling or other support to continue in their work, 30.9 per cent indicated that better financial compensation would be appreciated. In contrast, only 17 per cent of caregivers as a whole (i.e., NGO, government and people who provide informal help) indicated that some or better financial compensation would be useful. 44.7 per cent of those providing help through NGOs said they had incurred additional expenses in the process, compared with only 21.8 per cent among those helping through government agencies.

- Some 45.6 per cent of workers in NGOs had to change their social activities as a result of helping people with everyday tasks, compared with 37.7 per cent of those providing help through government agencies and 45.1 per cent providing informal support to family and friends.
- 45.6 per cent of those helping through NGOs experienced interrupted sleep patterns, compared with 37.7 per cent helping through government agencies and 28.9 per cent providing help to family or friends.
- Nearly a third (30 per cent) of those providing help through NGOs indicated that helping had affected their health, compared with 33.3 per cent providing help through government agencies and 21.2 per cent providing help informally.
- Only 73.2 per cent helping through NGOs reported living without pain or discomfort, compared with 96.9 per cent helping through government, and 81.3 per cent who do not help others with everyday tasks because of disability.
- 46.8 per cent of those helping through NGOs indicated that helping others left them sometimes or nearly always feeling that they do not have enough time for themselves, compared with 39.7 per cent in government agencies and 40.5 per cent who provide help informally.
- 57.7 per cent helping through NGOs said they sometimes or nearly always feel stressed helping others while meeting their other work and family responsibilities. This is slightly lower than among people who provided help through government agencies (60.9 per cent) or informally (53 per cent). However, 67.1 per cent helping through NGOs characterised their lives more generally as very or somewhat stressful, compared with 60 per cent helping through government agencies, 68 per cent helping informally and 57.9 per cent among those who do not help others with tasks due to disability.
- 40.9 per cent who helped through NGOs indicate feeling some level of burden in helping others, compared with 46.3 per cent of those in government agencies and 42.3 per cent who help family or friends because of disability.
- Most people who help others because of disability (92.1 per cent as a whole) did not indicate having to postpone plans to enrol in education or training as a result of helping. However, a lower proportion of people working in the NGO sector indicated the same (82.9 per cent).
- 27.7 per cent helping through NGOs said they have control over all of the decisions affecting their everyday activities, compared with 46.2 per cent helping through government agencies and 35.3 per cent in the adult population as a whole.
- 49.6 per cent helping through NGOs reported that they are very satisfied with their lives in general, compared with 43.7 per cent helping through government agencies, 50.4 per cent who help informally, and 55.5 per cent who did not help others due to disability.
- 69.5 per cent in NGOs who helped others because of disability said they sometimes or nearly always feel that they should be doing more for the people they help, compared with 88.6 per cent of those in government agencies and 61 per cent who help informally.
- 20.8 per cent helping through NGOs ever feel angry when around the person helped, compared with 20.1 per cent helping informally and 12.1 per cent helping through government agencies.

The NGO community sector of workers who help Canadians because of disability, then, is a highly gendered, predominantly female industry comprising workers who are comparatively older and well-educated, but with comparatively lower personal and family incomes. Many would appreciate better financial compensation so that they can continue to provide help. They are more likely than providers of disability-related help through government agencies to incur additional expenses as a result of their work.

Compared with the general population they work at their jobs fewer hours per week but for more weeks of the year. Many have experienced changes in sleep patterns, social routines and personal health as a result of their work. They are more likely than others on average to be living with some level of pain or discomfort. Many feel that they do not have enough time for themselves, feel stressed as a result of their work and stressed in general juggling work and family responsibilities. They are more likely than others who provide help to say they feel some level of burden in the process. They are more likely than others to have postponed further education or training because of their work and are less likely to feel that they have control over the decisions that affect their everyday activities. They are less likely than people who do not help others because of disability to feel highly satisfied with their lives.

Within the NGO sector of workers who provide everyday help because of disability, more than half (57.7 per cent) of the employees are unskilled and semi-skilled workers. Among these 150,000 people:

- The vast majority is female (74.4 per cent).
- Their estimated personal incomes ($16,700) and total household incomes ($41,800) are quite low as compared to Canadian adults as a whole ($26,000 and $47,600 respectively).
- They work on average 31 hours per week, 47 weeks of the year.
- Most (69.4 per cent) do not have a post-secondary certificate, and most (73.4 per cent) did not take any courses towards a certificate in the year when the GSS was conducted.

The sub-sample size for this group of workers is too small to allow for precise statistical comparisons with others. However, general analysis of the data indicates that unskilled and semi-skilled workers in the NGO sector who provide help in everyday tasks to people with disabilities are more likely than other low skilled people who help others to report the following:

- Greater financial compensation would be appreciated for extra expenses
- Changes in sleep patterns and affected health
- Postponed education or training

These workers in the NGO sector are less likely to report the following:

- Living without pain or discomfort
- Full control in the decisions that affect their everyday activities
- That they should be doing more for those they help.

Table 4 shows the numbers of workers in the community system experiencing various negative impacts as a result of providing disability-related help with everyday activities. Some of the figures would have been suppressed owing to small sample

Table 4. Employment impacts on people working in NGOs or government agencies and who of provide help with everyday activities because of disability

	Numbers affected	Per cent of all who provide such help through agencies
IMPACTS OF HELPING		
Made changes in social activities	217,000	51.2%
Changed holiday plans	132,000	31.2%
Postponed plans to enrol in education or training	78,000	18.8%
Changed sleep patterns	183,000	43.2%
Had extra expenses	160,000	37.8%
Caused health to be affected	132,000	31.0%
Sometimes or nearly always feel do not have enough time to self	186,000	44.1%
Sometimes (or nearly always) feel angry when around the person helped	76,000	18.1%
Sometimes or nearly always feel stressed helping others and meeting other responsibilities for family and work	247,000	58.6%
Sometimes or nearly always wish someone else would take over helping	128,000	30.5%
Sometimes or nearly always feel should be doing more for the people helped	317,000	75.3%
Sometimes or nearly always feel could do a better job of helping	300,000	71.3%
MEASURES THAT WOULD BE USEFUL		
(Better) financial compensation	114,000	27.0%
Something else (e.g., occasional relief, flexible work/study, info to be effective, info on nature of illness, counselling or other measures)	212,000	49.9%
Total helping through NGOs and government organizations	**425,000**	**100.0%**

sizes if a distinction were drawn between people working in NGO and government organisations. Accordingly, the distinction has not been drawn.

Table 5 shows the kinds of help that people provide through NGOs and government agencies. Personal care is the most widely provided help through these agencies. Assistance with italicised tasks is provided in addition to one or more of the non-italicised tasks.

Table 5. Kinds of help provided in everyday activities because of disability (by people working in NGOs and government agencies)

Child care	-	
Meal preparation, housecleaning or house maintenance	152,000	35.7%
Grocery shopping, transportation, or banking/bill paying	107,000	25.0%
Personal care	286,000	67.1%
*Checking up**	*55,000*	12.9%
Emotional Support	*99,000*	23.3%
Use of medical equipment or assistance with medication	*174,000*	40.9%
Socialising	*131,000*	30.8%
Obtaining information, making appointments, negotiating the provision of services	*104,000*	24.5%

* Small sample size. Use figure with caution.
Italicised activities are in addition to non-italicised (i.e., instrumental) activities.

D. The Community at Large — Generic Supports and Services

People with disabilities and their families also seek support beyond the specialised disability system. They want to be included with others who go to school, access employment, participate in recreation and access generic services and opportunities more broadly.

An inclusive community is one in which the principles[4] of equality, respect for diversity, fairness, individual dignity and responsibility, and mutual aid and responsibilities for one another are met. An inclusive community seeks to eliminate biases within society and in policies and programs that lead to the objectification of people and in their social and economic under-representation, marginalisation and exclusion based on their gender, level of ability, race, age, sexual orientation etc. In so doing, it seeks to identify and challenge pervasive and deeply established social attitudes, conditions and behaviours that contribute to these biases.

An inclusive community is a community that welcomes all persons, regardless of social differences based on gender, level of ability, race, aboriginal status, ethnicity, country of origin, age, sexual orientation, etc. An inclusive community assures persons' rights to self-determination, democratisation and equality, thus enabling all persons to enjoy equal status, to realise their human rights and full potential, to contribute to the political, economic, social, and cultural life and development of the community and to benefit from their participation.

To achieve these goals, an inclusive community ensures that measures are in place to compensate for historical and social disadvantages experienced by groups of persons. Measures would include changing the way social, economic or built environments are organised to eliminate barriers to participation and to provide supports and

services to overcome social disadvantage. In the case of persons with disabilities, this would include measures to compensate for disadvantages experienced because of particular conditions or long-term health problems.

A community that is inclusive of persons with disabilities would acknowledge that there is no such thing as a 'perfect' person, but rather that all persons have dignity, are unique and have their own unique potential, gifts and abilities. It would value that diversity and seek to ensure that the health and development of every person is encouraged and supported according to their unique needs and circumstances.

But many communities present significant barriers that reinforce the exclusion and disadvantages faced by people with disabilities. For instance, in any given situation in the community (e.g., workplaces, places of learning and recreation), a variety of accommodation measures may be needed to meet the diversity of needs among people with disabilities. In those situations, unavailability, inaccessibility, cost and lack of responsiveness to need can "conspire" to block effective participation.

Schools are cases in point. As communities in their own right, inclusive schools share the same characteristics and principles as inclusive communities. Thus, inclusive schools welcome and value all members of the community. They ensure that all students participate in classrooms with their age peers and are able to learn and to develop emotionally, socially, intellectually, physically and spiritually to their fullest potential. Inclusive schools put into place measures to support all students to fully participate in the life of the school with their age peers. Where barriers to full participation exist, inclusive schools change the way they are organised, adapting the physical premises and/or programmatic elements within classrooms to the needs of students.

Table 6. Number of working age students using/needing aids/devices or services for classes (HALS 1991)

	Total needing	Total using
Accessible buildings	11,000	6,000
Accessible classrooms	11,000	6,000
Accessible residences	6,000	3,000
Accessible washrooms	11,000	7,000
Suitable transportation	15,000	9,000
Other features	9,000	4,000
Total persons needing	**21,000**	-
Note takers, scribes and readers	8,000	6,000
Tutors	12,000	9,000
Attendant services	6,000	4,000
Oral or sign language interpreter	2,000	2,000
Computer access	10,000	8,000
Talking books	3,000	2,000
Hand held or desk mount magnifier	7,000	2,000
Braille texts	1,000	1,000
FM systems or tape recorders	7,000	5,000
Other aids/services	12,000	3,000
Total persons needing	**35,000**	-

Table 6 shows the extent of need for various accommodation measures for learning among working age students. The table shows that, while the majority of needs are met, there is a gap between the extent of need for various environmental supports and the supports actually available.

Turning to the community more broadly, for many people with disabilities, mainstream programs and opportunities that might facilitate their participation are in many instances not available, located too far away to be useful in any practical sense, or require reliance on inadequate transportation (**Tables 7 and 8**).

Table 7. Difficulties HALS respondents with disabilities encountered obtaining generic services, programs and opportunities because these were not available within a convenient distance or involved reliance on inadequate transportation

Services, Programs and Opportunities	Number of people affected
ADULTS (15 years and older)	
Needed health or social services are located too far away	50,000
Lack of nearby facilities or programs for greater participation in leisure activities	364,000
Lack of nearby facilities or programs for greater participation in physical activity	274,000
Transportation is inadequate to access needed health/social services	29,000
Transportation is inadequate for greater participation in leisure activities	188,000
Transportation inadequate for greater participation in physical activities	135,000
Transportation is inadequate for working-age people seeking work-related training	
— employed people with disabilities	12,000
— unemployed people with disabilities	4,000
— people with disabilities who are not in the labour force	18,000
Lack of accessible transportation a factor in discouraging people not in the labour force from looking for work	68,000
No jobs available a factor in discouraging people not in the labour force from looking for work	139,000
Desired literacy upgrading is not available to people with low literacy skills	8,000
CHILDREN (younger than 15 years)	
Lack of nearby facilities or programs for greater participation in physical activity	17,000
Transportation inadequate for greater participation in physical activity	11,000

Table 8. NPHS respondents (aged 12 and older) who felt that health care services were needed but not received, showing reasons relating to availability and transportation

Why health care not received	With disabilities	Without disabilities
any reason	467,567	658,374
not available in area	53,000	59,000
not available when required	81,000	103,000
waiting time too long	104,000	147,000
transportation problems	23,000	8,000

Where available within reasonable distance or with suitable transportation, generic services and opportunities are in many instances inaccessible (**Table 9**).

Table 9. Difficulties HALS respondents with disabilities encountered obtaining generic services, programs and opportunities because these were inaccessible

Services, Programs and Opportunities	Number of people affected
ADULTS (15 years and older)	
Work-related training which is sought is not accessible to...	
— employed people with disabilities	37,000
— unemployed people with disabilities	8,000
— people with disabilities who are not in the labour force	39,000
Information about jobs not accessible to people w/disabilities who are not in labour force	54,000
Needed health or social services are not accessible to people needing them	35,000
Facilities, equipment or programs for greater participation in leisure are not accessible	165,000
Facilities, equipment or programs for greater participation in physical activities not accessible	168,000
CHILDREN (younger than 15 years)	
Facilities, equipment or programs for greater participation in physical activities are not accessible	17,000

The sought-for generic services and opportunities for work, education, health and leisure may be available or within geographic reach, but in many cases are not be affordable (**Table 10**).

Table 10. People facing barriers to generic services and programs, showing numbers and percentages of people citing cost as a barrier to accessing the services sought * (HALS)

Support needed	Total number reporting any barrier to accessing needed service	Number reporting cost as a barrier	% reporting cost as a barrier
Health or social services	163,000	39,000	24.1%
Support for participation in leisure activities	1,277,000	522,000	40.9%
Support for participation in physical activities	1,651,000	380,000	23.0%
Work-related training to enhance skills / learn new skills (employed people)	120,000	36,000	30.0%
Work-related training to enhance skills / learn new skills (unemployed people	44,000	15,000	32.7%
Work-related training to enhance skills / learn new skills (people not in the labour force)	135,000	41,000	30.3%
To move to preferred accommodation	426,000	294,000	69.0%
Would need financial assistance to move	not applicable	276,000	—

Analysis of the NPHS found that 85,000 people with disabilities cited cost as a reason for not accessing needed health care services, compared with 113,000 people without disabilities.

Even if available within convenient reach, accessible and affordable, programs may not be responsive to the needs of people with disabilities (**Table 11**).

Table 11. Difficulties HALS respondents with disabilities encountered obtaining generic services, programs and opportunities because these were not relevant to needs or were unresponsive, showing number of people affected

Services, Programs and Opportunities	Number of people affected
ADULTS (15 years and older)	
Work-related training courses not relevant to needs of...	
— employed people with disabilities seeking training	17,000
— unemployed people with disabilities seeking training	6,000
— people with disabilities who are not in labour force seeking training	25,000
Desired literacy upgrading is not suitable to needs of people with low literacy skills	13,000
Long distance trips prevented because of non-supportive transportation staff	24,000
Assistance is not available for greater participation in leisure activities	192,000
Had to leave community to attend school	77,000
CHILDREN (younger than 15 years)	
Not presently attending school (children 5-14 years)	10,000
Had to leave community to attend school	29,000

Analysis of the 1996 NPHS found that 95,000 people with disabilities compared with 85,000 people without disabilities cited the inadequacy of service as a reason for not accessing needed health care services.

---

1 Owing to complexities in the structure of the GSS file, the figures those helped are based on family members who received help and who are coded as the first records of cases in the GSS, i.e., a random sub-sample of family members who provided help.

2 The figures on geographic proximity are based on family members who provided help and who are coded as the first records of cases in the GSS.

3 Figures in Table 3 are based on family members who provided help and who are coded as the first record of cases in the GSS.

4 These principles underpin the Social Union Framework Agreement.

IV

Key Policy Issues

A. Introduction

The research undertaken by The Roeher Institute identified a number of key policy issues concerning the disability support system in Canada and the challenges encountered by people with disabilities and their families in securing needed supports. While they may play out differently depending on age and life stage, and are compounded during the many and varied life transitions, a common set of underlying, systemic and issues emerged. A discussion of these multidimensional issues follows, as they affect A) persons with disabilities, B) their families, C) communities. They include:

Policy Issues For Persons with Disabilities

- System for identification/assessment, planning and co-ordination of needed supports
- Eligibility criteria
- Access to personal disability supports — in-home, community, developmental, school and employment
- Affordability of supports and services
- Supports for persons with disabilities to live independently in the community

Policy Issues For Families

- Recognition and support for contributions families make to the disability supports system
- Eligibility criteria
- Adequacy of family supports — in-home, community, employment-related according to identified need
- Cost to families

Policy Issues For Communities

- Inclusiveness of mainstream community services — recreation, school, workplace, health care, transportation, etc.
- Accountability for full citizenship and inclusion by community sectors and governments
- Investment in human resource development in the disability support sector, for training, education, wages and benefits, labour market development and collective bargaining arrangements
- Strategy for deinstitutionalisation of people with disabilities

B. Policy Issues for Persons with Disabilities

One of the key findings of the research is that many persons with disabilities in Canada are not receiving the supports they need to ensure their optimal health and development. There is a significant gap between the disability supports people need and what they actually receive. The extent of unmet need for various disability supports varies according to factors such as the sex of the person needing the support, the kind and severity of their disability, their labour market status, attachment to the income security system, family income, geographic location and age.

Issues of access to needed disability supports can be even more complex for people of First Nations communities and for visible minorities.

Unfortunately, currently available data sources have very little information about supports needed by children with disabilities and the gap between needed supports and the supports actually received.

Among adults, the largest numbers of people with unmet needs for help with everyday activities or for aids / devices:

- have moderate or severe disabilities
- are concentrated in lower income groups
- have very little paid employment income
- are not attached to the disability-income support or benefit system and
- are of working age.

Data from the *Health and Activity Limitations Survey* (HALS) help to paint a picture of the extent of unmet need. For example,

- Less than half (46.3 per cent) of the approximately 2 million adults who need help with everyday activities because of disability have all the assistance they need. About the same share (45.3 per cent) receive help, but need more of it, while 8 per cent need help and receive none. Major areas of unmet need include assistance with heavy household chores, regular housework and grocery shopping. There is also considerable unmet need for assistance with meal preparation and with personal finances.

Table 12. Extent of unmet need for help in everyday activities among adults with disabilities who need help because of their condition (HALS)

Type of help needed	% who get the help they need	% who get help but need more	% who get no help at all
Meal preparation	57.2	28.4	13.4
Shopping	63.1	25.5	10.5
Everyday housework	51.5	30.4	17.5
Heavy household chores	55.3	37.8	5.2
Persons finances	62.0	26.2	11.1
Personal care	52.7	27.2	17.8
Moving around at home	44.9	24.7	29.1

Table 12 shows the gap between the help that adults with disabilities need in everyday activities and the help available to them to fully meet those needs.

- We do not have comprehensive data on the gap between the human supports that children with disabilities need at home and the supports actually available. However, focus group respondents consistently indicated that this is a major problem.
- Generally, people needing assistive aids/devices have what they require. However, nearly 20 per cent of adults need more aids or devices than they are presently using and 11 per cent need such items and have none. Items most widely needed include: hearing aids and volume control telephones for people with hearing difficulties; glasses, contact lenses and magnifiers for people with visual impairments; canes, wheelchairs and back/leg braces for people with mobility impairments; and arm braces and various unspecified supports for agility. (**Appendix Tables 1 - 6**).
- While we have data on the numbers of children with disabilities who use various assistive technologies, large-survey data are not available on children's need for such technologies that are only partially met or completely unmet.
- One quarter (24.9 per cent) of the 254,000 adults who need external home modifications have none of the features they require. Approximately half (49.4 per cent) of the 219,000 people who need internal modifications to their home environment have none of the features they require. Widely needed internal modifications reported when HALS was conducted included grab bars, elevator or lift devices, bed or bath lifts and emergency call systems.
- Some 10,000 children with disabilities need modified features within the home that they do not have (**Appendix Table 7**).
- Nearly one-third of the 2 million adults with disabilities who regularly take medications because of their condition have expenses for drugs that are not reimbursed by any public or private plan. The costs of medications needed by some 79,000 children with disabilities are not reimbursed by any plan.

These unmet needs are the result of the interplay of diverse factors. From the initial diagnosis of a disability (whether at birth or months or years later), uncoordinated

and fragmented services, rigid institutions and regulations and negative attitudes result in a situation of inadequate supports. This compromises not only the health and well being of people with disabilities, but also their ability to engage in their communities as active citizens.

Participants in the research activities identified a number of issues requiring policy attention. These include:

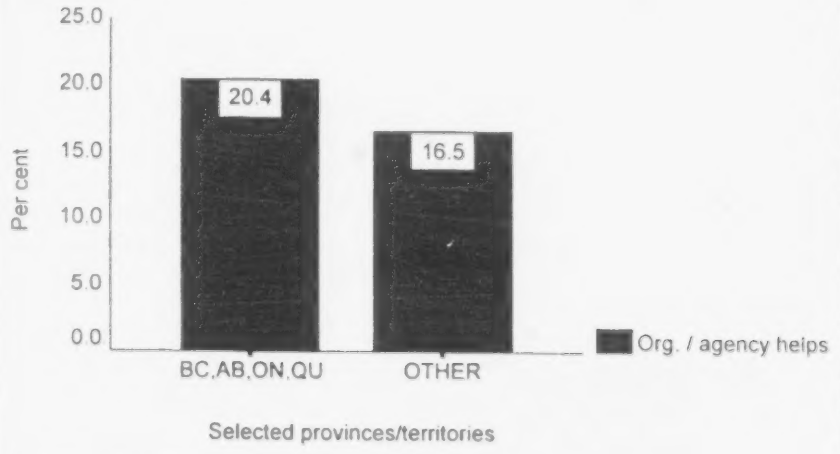
1. System for identification/assessment, planning and co-ordination of needed supports

Across the country, people with disabilities and their families expressed the clear need for a co-ordinated, holistic approach to personalised needs assessments, planning and co-ordination. Respondents called for a fluid, seamless national system that cares for the 'whole life of the person' – something that the current uncoordinated, fragmented, sectoral approach fails to do.

They cited the current approach as a hindrance to healthy child development, to the receipt of quality education and adequate incomes, to access to community activities and to paid employment, and as contributing to the breakdown of job situations that have been attained. They described how the current approach reduces people with disabilities to medical cases, educational issues, social risks and economic burdens. They spoke about how this resulted in their disenfranchisement as citizens, and ultimately to the devaluation of their personhood.

The lack of co-ordination reaches across and among provinces, communities, ministries (e.g., education, health, employment, social services, justice), key players in the employment system (employers and unions/employee associations), community agencies and families.

Figure 7. Adults with disabilities who need help in everyday activities: helped by community agencies, by selected region (percentages, working age people)



Source: The Roeher Institute based on HALS 1991

While *In Unison* lays out some broad directions for policy and service provision in the disability sector, it has not translated into a pan-Canadian policy framework or set of funding commitments. Without this, persons with disabilities are not assured access to a portable system of needed disability supports.

As such, people moving between provinces must learn a whole new set of systems and services with each move, as there is no co-ordinated, consistent approach across the country; there is no guarantee that supports and services received in one province will be available in another.

Specialised supports may be relatively available in one

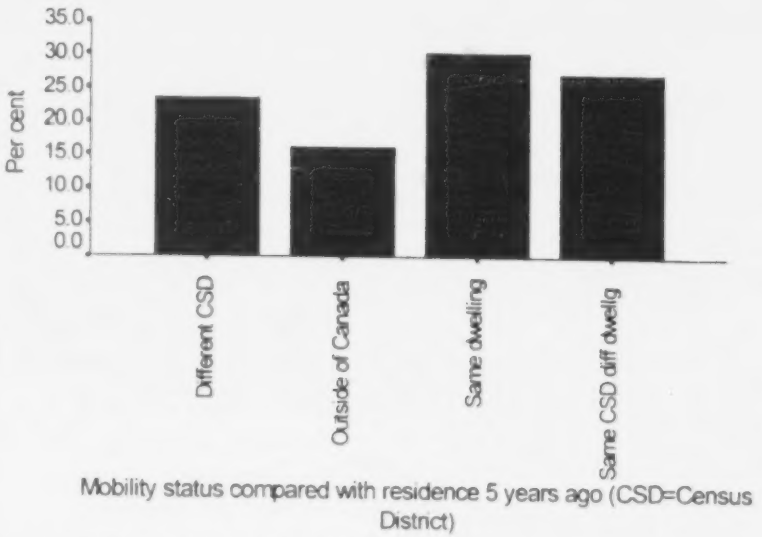
province (e.g., one of the wealthier provinces — **Figure 7**), community (e.g., a large urban centre or affluent health / social services region), or situation (e.g., at school). Such supports may not be, and in many cases are unlikely to be, equally available to the same person or family in another province or territory (e.g., a poorer one), community (e.g., a rural community), or situation (e.g., for greater participation in employment, physical activities or leisure activities after school). In addition, upon arrival in a different province or territory, it reportedly may take up to six months to qualify for various disability supports and then even more time to actually receive the needed supports. As a result, people's mobility rights are compromised.

Figures 8 and 9 show the percentages and numbers of people who need help with everyday activities, and who receive any help from community services. The figures present the information according to whether in the past five years, respondents have: recently moved into the country; have moved from one home to the next in the same census district; have moved from one census district to the next, or have remained in their same home.

The lesson to be drawn from the figures is that people who remain in the same home over a number of years are more likely than others to secure the help they need for everyday activities from community agencies/organisations.

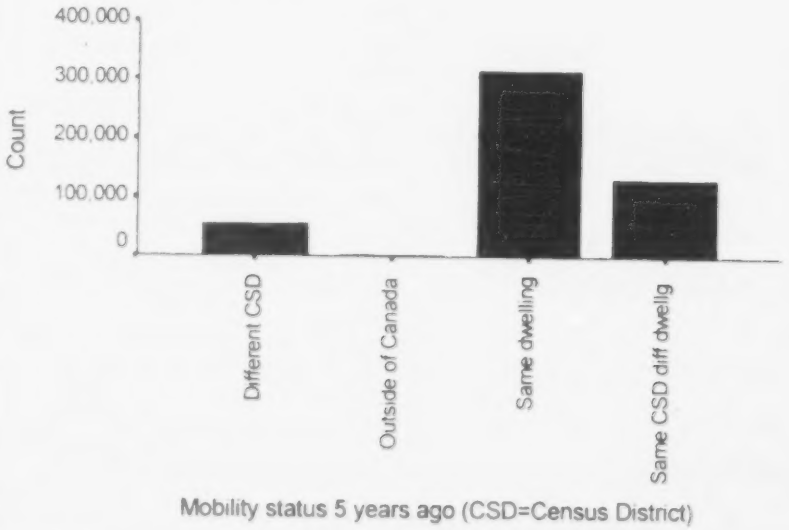
Respondents also spoke about the non-existence of a locus of

Figure 8. Percentage of people with disabilities who need help with everyday activities, who get community services, by mobility status



Source: The Roeher Institute based on HALS 1991

Figure 9. Numbers of people with disabilities who need help with everyday activities, who get community services, by mobility status



Source: The Roeher Institute based on HALS 1991

comprehensive information or organised point of contact for linkage to a "system" of support services. People cited how they typically were unable to obtain help to deal with various linkages and transition points, for example from hospital or mental health treatment centres to home, among various community services, from early childhood development to school-based programming.

Appendix Table 11 shows that people with disabilities who need various kinds of help with everyday activities are generally on their own to secure information needed to arrange for that help, or turn to family members for the needed information.

People with disabilities rely extensively on family members for obtaining information, making appointments or negotiating the provision of services. Family members comprise 80.8 per cent of the 992,000 people who provide such support in addition to helping with everyday activities.

As a result of the ineffective system for identifying people's needs for various supports and for facilitating access to those supports, many people presently receiving support have faced difficulties such as delays, finding good quality providers of support, finding compatible support and various other difficulties.

Major population surveys do not indicate the extent to which people altogether lack needed human support specifically because of ineffective needs identification and co-ordination measures. However, HALS enables identification of large numbers of people who lack needed human support for some reason. Relatively few of those who need more support than they receive are helped by community agencies (**Table 13**). HALS shows that many people lack needed aids / devices / supports because they do not know that such supports exist or do not know where to obtain them (**Table 14**).

Table 13. HALS respondents needing more help with everyday activities, showing numbers receiving help from community organisations/agencies

	Have some help but need more			Need help but receive none	Total needing more help
Help needed	Total with some help and needing more	Receive from voluntary agency	Receive from private agency		
meal preparation	145,000	17,000	49,000	68,000	213,000
shopping for necessities	210,000	8,000	34,000	86,000	296,000
housework	258,000	22,000	85,000	149,000	407,000
heavy household chores	547,000	27,000	149,000	76,000	623,000
personal finances	130,000	3,000	21,000	55,000	185,000
personal care	78,000	10,000	26,000	51,000	129,000
moving about at home	40,000	2,000	3,000	46,000	86,000

Table 14. Difficulties HALS respondents faced in obtaining selected disability supports because they did not know where to obtain the support or did not know the support existed*

Support needed	Do not know where to obtain	Did not know it existed
Specialised features needed to enter or leave home	12,000	
Specialised features inside the home	33,000	17,000
Aids / devices for people who are deaf or hard of hearing	35,000	8,000
Aids / devices for people who are blind or vision impaired	10,000	10,000
Aids / devices for people with mobility disabilities	23,000	5,000
Aids / devices for people with agility disabilities	7,000	3,000
Disability tax credit		1,141,000

*There is some overlap between respondents in the "do not know where to obtain" column as some respondents face cost issues with more than one kind of support. The same is true for the "did not know it existed" column.

Respondents in focus groups cited a need for partnerships or a team approach to co-ordinate all the resources, services and programs so that people with disabilities and their families could best obtain what they needed. They stressed that the team should include those with a disability and their families as knowledgeable experts and consultants, as well as the various professionals and service providers who play a key role. Ideally, those who plan the services would be involved in efforts to bring about a co-ordinated approach to meeting disability-related needs.

Respondents also stressed that, as much as possible, a core team should be involved beginning with the initial diagnosis and continuing through each transition point in childhood, through adolescence and into adulthood, identifying and responding to changing needs along the way. They stated that transitions were often more difficult because of lack of knowledge about the disability by educators and other professionals; this problem is compounded when new people get involved at each transition. Without a co-ordinated, seamless approach, people with disabilities and their families must start from square one at each transition point, having to re-explain 'everything from A to Z' to a revolving door of professionals and service providers. The more specialists involved, the bigger the maze and the potential to become lost in the system.

Respondents cited the diagnosis point as being a particularly difficult transition, whether the diagnosis was made at birth or later in life. Respondents spoke about the confusion around the diagnosis point, due to a lack of information, direction, co-ordination and support. Those receiving a diagnosis must navigate a huge, cumbersome web of services and often get tangled in the system, losing precious time, months and even years working through the maze on their own. Without information and a clear identification of needs, supports and services may not be put into place to bring about the earliest possible intervention.

Respondents underlined the importance of having an on-going team or partnership approach as children with disabilities return home from primary care to their families, or move into day care and pre-schools and into the school system. They stressed that transitions involved more than just a transfer of a file. Effective planning and co-ordination would help to demystify the new systems, institutions, placements and practices and would clearly lay out the roles and expectations for

each member of the team. As it stands now, family members must typically assume the responsibility of planning and co-ordination. Respondents called the planning strategies by family members extraordinary and difficult, saying that "only the professional is given a chair to rest on".

Respondents spoke about the lack of inter-departmental co-ordination between health, social services, education, advanced education and employment and the uncertainty over who will fund what. Parents of school-aged children spoke about the confusion around who funds school health and support services, and how this can result in children not receiving very much-needed supports and services.

Respondents cited many examples of how the absence of a team approach compounded the stresses they experienced. They spoke about how:

- Uncoordinated services resulted in administrative blocks
- Specialists make everything sound good on paper, but do not consider the daily stresses on the family or the complexity of their needs
- Doctors cover medical reports only and then leave parents on their own
- Hospitals tell parents to approach community service agencies for assistance without considering that they likely need help to navigate these cumbersome systems to avoid getting lost in the system
- People have to deal with service agencies that may not be knowledgeable about or sensitive to cultural differences and social habits
- Family members are expected to take over from nurses in the medical care, feeding, bathing, etc of people discharged from hospital, without instructions for treatment at home or information about services, referrals, etc.
- Access to and the quality of supports and services fluctuate according to the different approaches, visions, philosophies and methodologies of the various service providers and the upheaval that sudden changes in service provision can have on the lives of people with disabilities and their families
- Parents' time is taken up as the sole people responsible for co-ordinating workers at home, workers at school, etc. — presently all separate entities — and the tremendous toll on parents' time and energy
- Parents must tell and retell the complete stories from the beginning with every change in worker or professional, rather than having a proper dossier system to brief change-over of staff and maintain the fluency of services for each person
- Parents have little confidence/security in the service co-ordination where it is completely lacking
- Case reviews may take place once a year, but there are no co-ordinated efforts to assist with the 24-hour day that the family often puts in.

In some instances, effective policies and procedures are in place for transition planning. Researchers heard about measures to ensure that, for children making the transition from early childhood programs to elementary school, teachers were well briefed in advance and the necessary documentation about the child and their needs was transferred from system to system. Researchers also heard about school-to-work transition programs in which employers, teachers, school counsellors, parents, social services organizations and the student with disabilities were all involved in strategizing about employment options after school-leaving. In these cases there was

clear policy and program support for collaborative process and knowledge transfer.

However, responsibility for transition planning tends to fall largely to school districts and individual schools where clear policy and a sense of responsibility may be lacking. Staff may lack the time, knowledge and commitment to carry out transition planning. The quality of the planning is thus highly dependent on individual teachers and school counsellors.

Where transition plans do exist, they can be very sporadic and sketchy and may be targeted only for children and youths with certain disabilities. As well, established services do not necessarily meet the needs for optimum results for the child and family. The current process is not consistently mandated, student- or family-centred. As well, the process is not always collaborative and inclusive of all persons who should be involved. For example, school-based planning does not always include other community partners such as medical personnel, employers, social service staff, recreation leaders, etc.

In all focus group sites, respondents spoke about the very uneven, haphazard and even altogether absent process for planning for life beyond high school. While efforts may be made to identify young adults' visions for their lives beyond school-leaving age, in many instances this does not happen until late in the school career (e.g., last year or two of high school). It typically does not involve the range of people and organisations that should be involved in the process (e.g., school counsellor, employers, organisations that provide literacy enhancement or job-related training, post-secondary institutions, community providers of disability support services, parents and the young person with disabilities). Often students in special education classes do not have access to school-based vocational counselling, or school-to-work or youth-to-adult transition planning. Once young people leave school, there is no constant point of contact for ongoing planning and co-ordination of life and support options.

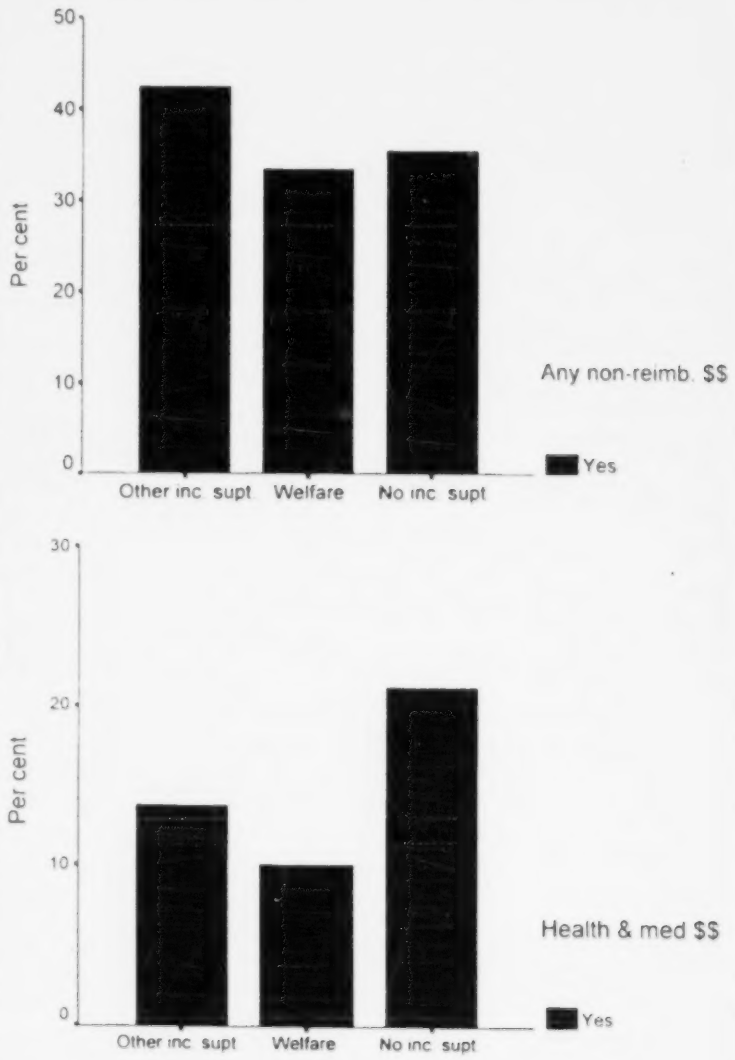
2. Eligibility criteria

For governments, determining eligibility for publicly funded services presents significant challenges. On the one hand, public financial resources are finite and have to be managed in a way that is fair, fiscally sustainable and accountable to the public at large — recognizing that at any given time demand for support may outstrip a government's fiscal capacity. On the other hand, people do look to government funded programs for assistance to meet legitimate needs, expect to be equitably treated in the process and ideally would have their needs adequately addressed in a way that does not result in major hardship to themselves.

Reconciling these competing challenges can be a difficult process. Various criteria and procedures for determining eligibility are developed to target finite resources to where they are most clearly needed. Yet, despite those efforts, people continue to "fall through the cracks" in the system.

Eligibility determination emerged in the research as a crucial issue for persons with disabilities. Their experience is that eligibility criteria often result in a restriction of options and opportunities at all stages and phases of their lives, compounding the stresses and challenges already being faced because of their disability and heightening the difficulties experienced during transition situations. Restricted and inflexible eligibility criteria were identified across the multiplicity of agencies and ministries through which persons with disabilities can access needed supports (i.e.,

Figure 10. Percentage of people with disabilities who have non-reimbursed costs, by attachment to welfare



Source: The Roeher Institute based on HALS 1991

human help, assistive technologies) and financial resources (i.e., basic income for food, shelter, clothing, utilities).

In many instances, formal criteria are established to control access to disability-related supports and services. These criteria are usually rigid and insensitive to personal needs, situations and circumstances. What a person is eligible for can depend on a combination of factors aside from their needs. Often, eligibility to supports and services is determined according to the income or age of the person with a disability, or is restricted or graduated according to the identified nature or 'severity' of the disability.

Income, or the presumed ability of the person with disability or of their family to pay for services and supports, is a primary screen for eligibility. For instance, a person who is employed at a job that pays low or moderate earnings may be presumed by governments as able to pay for their power wheelchair. However, the wheelchair could cost thousands of dollars and be unaffordable on the basis of job earnings in the event that a replacement is required. In contrast, a person on social assistance may have the wheelchair largely covered as an in-kind benefit.

Where the latter is the case, assets above a certain level typically disqualify people from accessing or retaining income support and extended health (e.g., assistive devices, medications, attendant services) and dental benefits. Such provisions require that people continually "spend down" their assets to allowable limits, depriving themselves of long-term financial security in the process.

Eligibility for extended benefits is in many instances compromised when persons make the transition from provincial income support programs (e.g., welfare and disability-specific income programs) to paid employment. In some jurisdictions, provision has been made to support such transitions. Typically this involves a grace period in which people are permitted for a period of time (e.g., three months) to have employment earnings above the level permitted for people receiving income support. During that period of time, an individual can receive extended benefits. Beyond that time, however, people with disabilities would not qualify for the benefits. Where a person's net earnings would not be sufficient to meet needs that

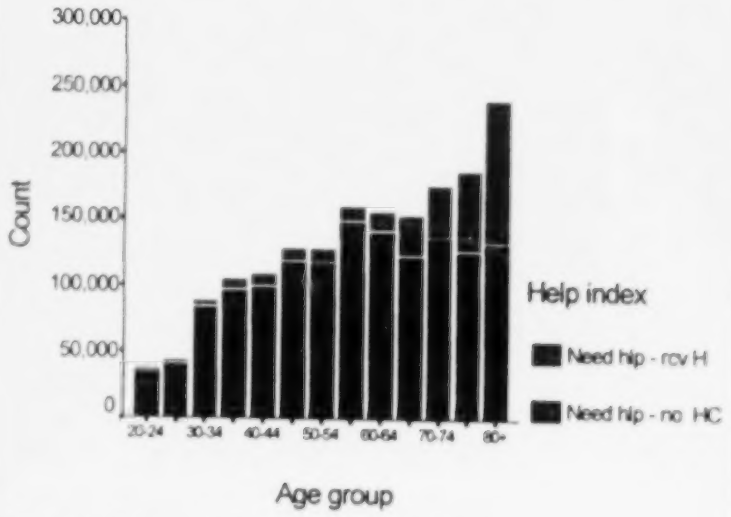
would otherwise be covered by the public plan, the prospective loss of benefits is a serious deterrent to making the transition to employment. This is especially the case where a person facing high disability-related costs is contemplating an employment situation that does not provide access to employee benefits of similar value to the benefits received under the public plan.

Figure 10 shows the extent to which people face non-reimbursed costs for disability-related goods and services in light of whether people receive income/benefits because of disability from the provincial welfare.

Eligibility may also be referenced to age rather than to the kind of support that a person requires. For instance, physiotherapy may be available to a child at little or no cost to the family. Young adults who have reached school-leaving age may have no access to such services funded at public expense. Similarly, a child may qualify for publicly funded in-home nursing support, personal care or personal assistance in recreational activities, whereas an adult may not be eligible for such services, or may be eligible but expected to pay for the services without reimbursement.

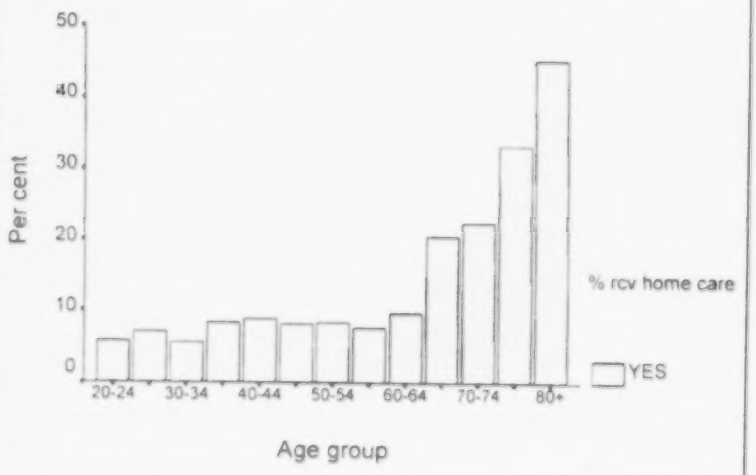
Figure 11 shows the number of people with disabilities in various age groupings who need help with everyday activities and who receive "home care" services paid for entirely or mainly by government. The figure shows that, as people age, the need for help increases. Access to funded services also increases with age, suggesting an age bias in eligibility rules. **Figure 12** shows the same information, but presents the percentages of people in various age groupings who need help and who receive home care services.

Figure 11. Home care received: people with disabilities by whether help is needed in activities (age group)



Source: The Roeher Institute based on NPHS 1996-97

Figure 12. Among those who need help, per cent who receive home care (by age group)



Source: The Roeher Institute based on NPHS 1996-97

Eligibility criteria based on the nature or severity of the disability compound these difficulties. For example, to secure in-home assistance for personal care (e.g., washing, dressing, and grooming), people typically have to qualify for home care, as this tends to be the "delivery system" for such services. However, they may not be able to secure a medical diagnosis that matches the eligibility requirements or

Figure 13. People needing help with everyday tasks, health status and whether receive home care services

Source: The Roeher Institute based on NPHS 1996-97

Table15. Numbers of HALS adult respondents without the needed aids/devices for disability because their condition was "not serious enough".

Aids for persons who are deaf or hard of hearing	54,000
Aids for persons who are blind or vision impaired	6,000*
Aids for persons with mobility disabilities	32,000

*Small sample size. Use figure with caution.

provide other evidence of a medical need. The "disease model" of disability is still pervasive in policy and practice, in the delivery of home care.

Figure 13 shows the percentage of people who need help with everyday tasks and who receive publicly funded home care services in relation to their health status index (HSI) score. The HSI is a proxy measure of severity of disability. Those with the highest HSI scores have fewest reported difficulties with hearing, seeing, speaking, movement, pain and so on. The figure shows that, for the universe of people who need help with everyday tasks because of disability/health condition, publicly financed home care services are much more widely available to people with low HSI scores than to people with higher scores.

Table 15 shows the numbers of people without the needed aids/devices because their condition is "not serious enough".

Besides these formal eligibility criteria, there is another set of unwritten rules, discriminatory practices and negative stereotypes that restrict eligibility to community-based programs and services. Thus, having a disability becomes a criterion for ineligibility to a broad range of activities and options open to those without disabilities.

Formal and unwritten eligibility criteria and the tension between them begin to play out around the diagnosis point. Sometimes obtaining a diagnosis can be quite problematic, especially when there are no clear-cut signs and symptoms. Among focus group participants, there was a feeling that doctors protect themselves in case of error, sometimes not giving a diagnosis for 3 to 4 years. As diagnosis is often used as an indicator of need and as a measure for eligibility for supports, without a clear diagnosis needs often are unidentified and unmet, compounding the effects of the disability. **Table 16** shows the numbers of HALS respondents without needed aids/devices because these were not prescribed.

Thus, on the one hand, there is considerable pressure to secure an accurate diagnosis. When funding criteria are tied to the severity of the disability, there may also be pressure to exaggerate the problem, leading to a focus on the person's inabilities rather than on their abilities. On the other hand, there may be a reluctance to have a disability diagnosed or identified given the potential for

Table 16. Difficulties obtaining selected disability supports because the supports were never prescribed or need was not certified by physician (HALS respondents)

Aids / svcs for people who are deaf or hard of hearing	60,000
Aids / svcs for people who are blind or vision impaired	10,000
Aids / svcs for people with mobility disabilities	27,000
Aids / svcs for people with agility disabilities	*6,000
Disability tax credit	168,000

*Small sample size. Use figure with caution.

discrimination and exclusion, leading to a situation where the person's disability-related needs are not met.

The effects of these restrictive and inflexible eligibility criteria begin to be felt during infancy and the pre-school period and are manifest throughout the life cycle in a variety of ways. Eligibility criteria based on type of disability are used to restrict access to pre-school disability-related services for some children. For example, access to early intervention programs is usually restricted to infants and pre-schoolers who have been identified with developmental delays. Parents of visually impaired or blind children described how they fought to have access to early intervention programs after specialised pre-school vision services for their children were discontinued in their jurisdiction over a number of years. Only by arguing that their children were developmentally delayed, or would become so without early intervention services, did they succeed in having the eligibility criteria loosened. In the end, eligibility was granted only to children attending day care or pre-school programs; those being cared for by their mothers at home remained excluded. For some children and their families, the years-long battle meant that they received no vision services throughout their pre-school years, with profound implications on many levels when they entered the school system.

Access to community-based pre-school programs can be difficult once a child is identified as having a disability. Parents spoke of the difficulty in finding pre-school programs that welcomed their children with disabilities. Some programs overtly excluded children with disabilities, while in other cases exclusion was covert. For example, programs restricted to toddlers who are toilet-trained may unintentionally discriminate against children for whom this will never be a possibility.

As children with disabilities move into school age, they are transferred from the medical and social service system to the educational system. Parents cited this as a point when many services their child had received as a pre-schooler stopped being provided or were not provided in a way that fully met their child's needs.

For example, once children reach school age, they typically no longer are eligible for the early intervention services they received as pre-schoolers. The expectation is that schools will provide the necessary interventions (See Figure 1). In reality, this often does not happen. This is a particularly difficult transition point for parents, and the beginning of a years-long struggle to ensure that their children's needs are met.

Children struggling with unidentified disabilities may suffer because of restrictive

Table 17. Professional assessment of children with disabilities (aged <15) for educational needs (HALS)

Never assessed	218,000
Assessed	153,000
Who assessed...	
— psychologist or psychiatrist	76,000
— social worker	23,000
— special education consultant	83,000
— therapist	65,000

eligibility criteria for testing. For example, in some jurisdictions, students have to wait until they have fallen two grades behind their age peers before they are eligible for an assessment for learning disabilities. For children attending private schools, there is no publicly funded assessment, imposing an additional financial burden on families. Without an assessment and diagnosis, children are not eligible to receive educational and support services, compromising the children's learning and increasing the likelihood of behavioural problems, low self-esteem and school drop out.

Table 17 shows the extent to which children less than 15 years of age reported in HALS had been assessed for their educational needs.

On the other hand, a low Intelligence Quotient (IQ) score test result is used to stream children out of mainstream classes and into special education classes or schools. Parents described the battle that ensued, and continued throughout their children's school years, when they chose to fight to keep their children in mainstream schools. Others spoke of the frustration of losing the battle, and of the rejection and loss experienced by their children when they were no longer eligible to attend the same school or class with their siblings and friends.

IQ is also used to determine eligibility for other programs such as developmental services. For some persons, the IQ threshold is too high for the person to qualify for needed services. For example, behavioural support may be available to a person with an IQ at or below 70. A person with foetal alcohol syndrome who needs behavioural support services but whose IQ is 90 would not qualify.

Parents described how artificial and rigid eligibility criteria resulted in unmet needs, in negative educational outcomes and in considerable frustration for students with disabilities and their parents. In one jurisdiction for example, parents explained that visually impaired students are eligible for black and white closed circuit televisions (CCTV) for in-school work. Their requests for a colour CCTV for their son — a primary student who was learning colours — were refused, even when they offered to pay the cost difference. Lack of access to this technological support is compromising the child's learning and development.

Eligibility for services is often determined by school budgets rather than the child's needs. Parents described how this resulted in them having to exaggerate their children's disability, and resulted in a focus on the children's deficits rather than on their gifts and abilities.

Parents spoke of the unfairness of criteria — as in the case of pre-school services — that restrict eligibility to certain supports and services, depending on the severity of disability. Respondents described how in some jurisdictions, a totally blind student might be eligible for and receive a personal assistant and adaptive technology, whereas one who is visually impaired may receive an occasional visit from a vision consultant — or nothing at all.

As youths with disabilities move from high school into post-secondary studies or employment, restrictive eligibility criteria add to their bumpy ride through one of

the most difficult transitions in life. The research found that students with disabilities have limited access to options open to other young adults (e.g., further education, job with an employer, self-employment at a small business, travel). Restrictive entrance criteria and testing and highly competitive job application processes result in the exclusion of many young people with disabilities from schools for higher education and jobs open to their peers without disabilities.

In some cases, eligibility for publicly financed job training / post-secondary education requires that the individual be able to sustain full-time enrolment — an "all or nothing" approach. Issues of stamina and fatigue arising from disability may preclude full-time enrolment, effectively disqualifying the person from accessing the services and opportunities needed for economic participation and income security.

Low literacy levels at school leaving may also disqualify students with disabilities from post-secondary training and other programs. This is especially a problem when students have learning or intellectual disabilities, or where issues of illness and fatigue, or lack of access to tutorial and other support services in the school years, leave them without skills comparable to those of age peers at school leaving. Post secondary institutions concerned about diluting their academic standards typically make little provision (e.g., modified curricula and teaching methods) for young adults in this situation. As these people do not meet the entrance requirements, they are effectively disqualified from furthering their education until they can meet the entrance standards. This places them in the untenable position of having to access alternative learning resources until they qualify for further knowledge and skills-development within the regular post-secondary and training system.

3. Access to personal disability supports — in-home, community, developmental, school and employment

Focus group respondents consistently identified lack of access to disability supports as a major problem. A needed support may be simply unavailable in a given part of the country or provincial sub-region or municipality. By the same token, if available the support may not be provided within a convenient distance from the person who needs it, may involve reliance on transportation services that may not exist or are inadequate, or may involve waiting lists and delays. In effect, the supports are not available in any practical sense.

Table 18 shows the extent to which the real or perceived lack of availability of various specialised supports is a factor inhibiting access to supports needed by adults. Current data sources do not allow the drawing of a similar picture concerning children with disabilities.

As a result of limited availability of needed specialised supports:

- Children and adults with disabilities often lack the level of support they require
- Waiting lists for support services abound
- Parents must continually take an extremely active role in furthering the interests of their child vis à vis various systems (e.g., education, social services, health, mental health), causing parental stress, burnout and poor health
- There can be a "constant battle" by family members of children with disabilities and by adults with disabilities for basic entry to programs and social/economic opportunities around each transition, and for full integration and inclusion at

Table 18. Difficulties HALS respondents encountered obtaining specialised disability supports because the supports were not available, showing numbers of people affected

Unavailable Support that is Needed	
ADULTS (15 years and older)	
Aids/services for people who are deaf or hard of hearing not available	26,000
Aids/services for people who are blind or vision impaired not available	7,000
Aids/services for people with mobility disabilities not available	7,000
Aids/services for people with agility disabilities not available	*4,000
Assistance not available for participation in leisure activities	192,000
Attendant not available for participation in physical activities	135,000
Unable to move to preferred accommodation because independent living support services are lacking	30,000
Housebound because attendant not available to help leave home	57,000
Housebound because attendant not available at destination	84,000
Specialised bus or van service is not available in the community	645,000
Specialised bus or van service is needed and is not available in the community	74,000
Prevented from leaving personal residence because lack of accessible transport.	47,000
Prevented from taking long-distance trips because appropriate transportation to/from terminal is lacking	55,000
Cannot easily obtain information about specialised transportation services and facilities needed for long distance travel	465,000
CHILDREN (younger than 14 years)	
Specialised bus or van service is not available in the community	81,000
Specialised bus or van service is needed and is not available in the community	9,000

*Small sample size. Use figure with caution.

transition points and thereafter

- Children and adults may be delayed in making important transitions (e.g., from pre-school programs to school; from high school to post-school programs, post-secondary education or to employment) owing to apprehensions — or to certain knowledge — about the non-availability of supports in the new situation
- Parents of children with disabilities may become reluctant to share information about how they obtained scarce supports with other parents because they fear losing the support they have secured if "word gets out"
- If needed supports for children are not available, parents (and to a lesser degree, other family members) become that support by default
- If needed supports for adults are not available, their spouses/partners and adult children become providers of support by default.
- Family members may contemplate and may eventually seek institutional and other

forms of out-of-family placement in the interests of securing needed supports.

Negotiations for needed supports and services can result in lengthy delays and interruptions of treatments, or in some cases, the realisation that the required support or service is unavailable, not funded at the same level as previously, or not funded at all.

4. Affordability of supports and services

Costs put disability supports and services out of practical reach for many people with disabilities. In many cases, a person qualifies for a given support, but he or she may not be able to afford it. This would happen, for instance, where a co-payment required for a publicly subsidised support is unaffordable, or where available supports are financed entirely by user fees and where the person or family lacks the needed income. Cost of specialised supports to persons and families was consistently reported in the focus groups, as in HALS, as a major factor impeding access to needed specialised supports.

Table 19 shows the numbers of people unable to access needed disability supports because of cost.

Table 19. Adults facing barriers to specialised disability supports, showing numbers and percentages of people citing cost as a barrier to accessing the supports needed* (HALS)

Support needed but not used because...	Total number reporting any barrier to accessing needed support	Number reporting cost as a barrier	% reporting cost as a barrier
Specialised features inside the residence too costly	148,000	77,000	51.6%
Aids/services for persons who are deaf or hard of hearing too costly	181,000	70,000	39.0%
Aids/services for persons who are blind or vision impaired too costly	45,000	23,000	50.1%
Aids/services for persons with mobility disabilities too costly	140,000	80,000	57.2%
Aids/services for persons with agility disabilities too costly	23,000	9,000	37.4%

Available data do not allow for a complete analysis of the range of supports not used because of cost. The data do, however, allow for a picture of the extent to which persons with disabilities are paying for some of the supports they use (**Table 20**).

For many persons with disabilities the effect of the extra costs of needed supports is compounded by low incomes — often the result of inadequate financial and labour market supports. For instance, in some jurisdictions, labour standards require that employers pay employees for a full shift, even if they are able to work for part of a shift only. This measure is a disincentive for employers to hire people who cannot work regular shifts and hampers the transition to the regular labour market as part-time employees. As a result, individuals' ability to earn money to pay for the

Table 20. Number of HALS respondents with non-reimbursed expenses for disability supports

Support used because of disability	Number reporting non-reimbursed expenses	
	Children (<15 years)	Adults (15 years and older)
Meal preparation		75,000
Grocery shopping		63,000
Everyday housework		162,000
Heavy household chores		444,000
Management of personal finances		21,000
Personal care		36,000
Moving about at home		14,000
Prescription and non-prescription drugs	79,000	886,000
Disposable items needed for health condition	23,000	107,000
Purchase & maintenance of specialised clothing, aids, medical supplies and equipment	37,000	235,000
Health and medical services not covered by any insurance plan	20,000	223,000
Modifications to residence because of health condition	9,000	41,000
Tuition or residence fees	20,000	
Transportation to/from treatment, therapy, rehabilitation, or extra expenses due to the need for more costly transportation	50,000	355,000
Personal services (e.g., attendant, home care, housekeeping)	14,000	139,000
Other (e.g., sign language interpreter, guide dog, etc.)	11,000	42,000
Expenses claimed under Medical Expenses Tax Credit		484,000

supports they need is diminished. Even people with middle incomes and significant out-of-pocket expenses experience difficulties meeting those costs.

Where paid jobs with employers or self-employment provide only low incomes, people need income supplements to meet their basic needs for food and shelter, and for needed disability-specific supports. If such supplements are not available, there is little incentive to make the transition to the paid labour force.

To complicate matters, unions may consider that informal employment-related support provided by family members and co-workers is work that should be performed by paid employees under the terms of contracts with employers. In some instances unions have barred the provision of such informal support, in turn resulting in job loss for people with disabilities.

5. Supports for persons with disabilities to live independently in the community

Focus group participants expressed the view that institutional and other out-of-

family placements of people with disabilities are on the rise owing to the difficulties faced in accessing needed supports in the community. To secure needed supports, people are reportedly opting for institutional or other arrangements outside of the family unit, as in some cases this seems to be the only way to secure the supports. This results in significant emotional trauma to children and adults with disabilities and to their families.

Available statistical data tend to confirm continued reliance on institutionalisation. The Residential Care Facilities series within Statistics Canada's Health Reports has presented data since the late 1980s on the numbers of people residing in various kinds of regulated, approved or funded facilities under the jurisdiction of provincial ministries of health and/or social services. These facilities range in size from 4 bed group homes to large, congregate care institutions, excluding hospitals. The most recent data are for 1997-98.[1] The Roeher Institute obtained unpublished comparative statistics for the 1993-94 and 1997-98 reporting periods. **Table 21** provides a summary of that information.

Table 21 shows that, overall, the number of institutional residents declined slightly in reporting facilities across the reporting years; in 1997-98 the number of residents was 99.1 per cent that of 1993-94. However, there were slight increases in the numbers of institutional residents in the 0-17 and 18-44 age groups. Particularly large increases occurred in the 18-44 age group in facilities for people with alcohol/drug problems, for the aged, for people with psychiatric disabilities (excluding psychiatric hospitals) and for transients.

The total number of people residing in residential care facilities is higher than the figures reported on the bottom row of the table. This is because the numbers of residents reported on the bottom row represent figures for facilities that reported in

Table 21. Number of residents in residential care facilities in 1997-98 compared with 1993-94, expressed as percentages, by age grouping, for facilities reporting in both years

	Number of residents in 1997-98 as compared with residents in 1993-94, presented as percentages		
	0-17 years	18-44 years	All ages
Alcohol / Drug	66.3%	116.7%	96.9%
Aged	*44.4%	135.7%	99.0%
Emotionally Disturbed Children	*114.8%	82.6%	107.8%
Developmentally Delayed	90.7%	88.5%	92.2%
Physically Challenged	*84.4%	93.9%	101.2%
Psychiatrically Disabled	*266.7%	122.4%	101.6%
Delinquents	106.1%	64.0%	99.1%
Transients	*255.6%	201.0%	121.6%
Other	112.6%	97.5%	103.8%
All facilities reporting both years	**106.8%**	**106.0%**	**99.1%**
Number of residents 1997-98	3,683	11,470	112,831

* Very small numbers of residents reported for these cells.

both years. For instance, 4,750 facilities were operating in 1993-94 and 3,382 in 1997-98, but only 2,414 of these facilities provided information to Statistics Canada in both years.

Table 22 shows the average number of people residing in residential care facilities in 1993-1994, 1997-1998 and across both reporting years, for facilities reporting in either or both years. For facilities reporting in both years, the average number of "residents" is about 47. For facilities reporting in either year, the figures show an overall increase from 39 to 44 people on average.

The figures suggest that, despite governments' enunciated commitments to furthering more personalised approaches to support outside of institutional arrangements, progress has been slow.

Table 22. Average number of people in residential care facilities that reported in 1993-94 or 1997-98 or across both years

	Facilities reporting in 1993-94 or 1997-98		Facilities reporting in 1993-94 and 1997-98	
	Average number of people		Average number of people	
	1993-94	1997-98	1993-94	1997-98
Alcohol / Drug	18.5	19.9	19.9	19.3
Aged	72.3	78.6	82.9	82.1
Emotionally Disturbed Children	9.6	12.6	11.0	11.8
Developmentally Delayed	13.7	15.6	16.4	15.1
Physically Challenged	13.2	19.3	17.0	17.2
Psychiatrically Disabled	16.8	17.5	18.6	18.9
Delinquents	17.9	19.2	19.5	19.3
Transients	71.4	98.8	82.7	100.6
Other	13.2	12.9	12.5	13.0
Total	**38.5**	**43.8**	**47.2**	**46.7**

Data on children with disabilities living in extra-family situations are sketchy. However, among children from birth to age 11, only 70 per cent were living with both biological parents compared with 79.1 per cent of children without disabilities when the 1994-95 National Longitudinal Survey on Children and Youth was conducted.

6. Summary of issues for persons with disabilities

Researchers heard a consistent message from all focus groups across the country: without adequate supports and services, particularly around transition points, people with disabilities undergo unnecessary hardship and are prevented from full and active participation in the social and economic life of their families, communities and country.

HALS is a useful source of statistical data for shedding light on key life situations in which people with disabilities find themselves and the transitions that they make. Appendix Table 8 uses the need for and access to adequate levels of help with everyday activities as a basis for looking at differential employment and financial situations of people with disabilities. The table also looks at their education and training, their geographic mobility, their social relations, issues of emotional affect and personal control, and their involvement with the community and social services system.

The data show that, compared with people who have no need of help or whose needs have been fully met, people fare less well across a range of situations where they receive some help with everyday activities but need more help than is available to them.[2]

- Such persons are more likely to be facing employment, income and expenditure challenges. For instance, they are less likely to be employed or to have worked for pay in the past two years and less likely if outside the paid labour force to have looked for work in the past two years. They are also less likely to report that they intend to look for work in the next 6 months. They are more likely to consider themselves completely prevented from working because of their condition; more likely to believe that they have been refused a job, promotion, access to job training or that they have been terminated in employment because of disability. If presently employed, they are more likely to have changed jobs because of their condition. They are more likely than others to need one or more job accommodations. Their estimated personal incomes from all sources are lower and they are more likely to be attached to the disability income system. They are more likely to have non-reimbursed disability-related expenses.
- While slightly more likely to be enrolled at school, college or university than people who have all the help they require, they are less likely to have completed schooling beyond high school graduation. They are more likely to consider their reading and writing skills inadequate for daily life and are less likely than others to be planning to upgrade their literacy skills. If they acquired their disability before completing their formal schooling, they are more likely than others to have had various difficulties completing their education.
- They are less likely to have moved in the past five years, more likely to consider themselves housebound, more likely to be completely prevented from taking long distance trips or to have difficulties in this connection, and more likely to be in communities where they have difficulties accessing local transportation.
- They are more likely to be divorced, separated or widowed and to be dealing with loneliness and depression; more likely to be prevented from doing activities because of pain/discomfort; and more likely to feel that they have little or no control in the decisions that affect their everyday lives.
- They are more likely to want more involvement in leisure and physical activities and to be uninvolved in those activities because the assistance needed from others is not available, and more likely to have had difficulty accessing health or community services in the past three months.

The analysis found the same general pattern in most instances controlling for severity of disability and access to adequate assistive aids/devices when needed.

It is difficult to show a direct causal link between access to the needed disability

supports and people's involvement in a range of economic and social activities. Nonetheless, the experiences of focus group participants and the overall findings based on statistical analysis are compelling. People with inadequate levels of support fare less well than others across a range of social and economic situations. Such persons find it more difficult to make transitions into socially and economically valued activities, and because of their disability find themselves in some cases having to make transitions that others would not (i.e., change of jobs, career path, course of study, school or community).

C. Policy Issues For Families

The research found that just 4.8 per cent of the 1.854 million adults with disabilities who need support with everyday activities because of disability receive all the help they need and are receiving supports and services from community agencies at no net cost to themselves.[3] Families struggle to fill in the gap, relying on extended family members, friends and out-of-pocket expenditures to support their own efforts. Needed are measures that are respectful of families' willingness to invest in their family members yet supportive of families and their overall health, development and social inclusion. The key issues for families requiring policy attention identified by participants in the research activities include:

1. Recognition and support for contributions families make to the disability supports system

Family members are the backbone of the disability support system in Canada, accounting for 73 per cent of all care providers.

By and large, people who help other family members with needs arising from disability do so willingly and do not feel over-burdened by the responsibility. However:

- 6.0 per cent (134,000 people) feel "quite a bit" or "extremely burdened. A further 14.6 per cent (or 323,000 people) feel "moderately" burdened in helping their family members because of disability.
- 24.8 per cent (545,000 people) report that their health has been affected as a result of providing care to family members with long-term conditions.
- The sleep patterns of 32.3 per cent (723,000 family care providers) have changed as a result of providing care to family members with disabilities.
- 17.0 per cent (378,000) of family members who provide help because of disability report that they "nearly always" feel stressed in juggling their responsibilities for helping their family members with disabilities while trying to meet their other family and work responsibilities.
- 12.5 per cent (278,000 family care providers) nearly always feel that they do not have enough time for themselves.

In view of these figures it is not surprising that at least 16.6 per cent (373,000 people) of those who help family members because of disability say that occasional relief would enable them to continue providing help. Unfortunately, in many cases needed supports are either not available or are not provided in a way that meets the family's needs.

For example, mothers of children with disabilities who participated in earlier research activities of The Roeher Institute, reported providing an average of 50 to 60 hours per week in disability-related care on top of other paid and unpaid work responsibilities. This compromised not just their own health, but also the well being of other family members[3]. (Analysis of the GSS found 85,000 family members who provided disability-related help for 44 hours per week on average.) In addition, inadequate disability-related supports and services exacerbate the stresses on families, contributing to detrimental outcomes. Family breakdowns are also more prevalent due to these inordinate strains, as evidenced by the over-representation of children with disabilities in stepfamilies, single parent families and foster families (33.2 per cent compared with 24 per cent among children who do not have disabilities).

While not all families have such an extremely heavy load, the number affected is considerable. Some 1.89 million people who provide help to family members with everyday activities because of disability say that they experience at least one of the following effects:

- making changes in social activities or holiday plans;
- postponing plans to enrol in education or training;
- having to move in with or closer to the supported family member(s);
- turning down a job offer;
- changing sleep patterns;
- incurring extra expenses;
- experiencing effects on personal health;
- seldom (i.e., nearly always not) having enough time to oneself;
- nearly always feeling stressed between helping others while trying to meet additional responsibilities for family or work;
- nearly always feeling angry around the family member helped;
- rarely or never feeling that helping has given back what life has given to oneself in the first place;
- nearly always wishing that someone else would take over responsibilities for helping;
- nearly always feeling that one should be doing more for the family member(s) helped;
- nearly always feeling that one could be doing a better job of helping; or
- feeling "extremely" or "quite a bit" burdened in helping family members.

While in many cases family members are the primary providers of disability supports, they are not entitled to the same benefits, vacation, sick leave and pensions as their paid counterparts, all of which would help to ease the weight of responsibility. Instead, focus group respondents spoke about the need to be 'on duty' 24 hours per day, 365 days per year.

2. Eligibility criteria

In their search for supports and services, families often encounter rigid eligibility criteria that are insensitive to their needs, situations and circumstances. As with criteria that restrict access for people with disabilities, eligibility for family supports and services is also often determined according to the income or age of the person with a disability, or is restricted or graduated according to the identified nature or 'severity' of the disability.

The experience of many family members is that eligibility criteria result in a restriction of options and opportunities that limit the potential for family members to be fully engaged in their communities and to have a life independent of their care-giving responsibilities. For example, criteria that limit work-place flexibility for persons caring for a family member with disability can result in either the loss of employment or employment situations that may be more flexible but which are also more precarious with low-wages and few benefits.

For many, such restrictions lead to a life of greater poverty and social isolation. For example, among people (GSS respondents) who provide 20 hours per week or more help to family members with everyday activities, 67.4 per cent (97,000 people) indicate that one or more measures would be helpful in enabling them to continue providing help (e.g., occasional relief, financial assistance). The average household income among people providing this level of weekly assistance to family members is $38,020. They have 5.8 close friends on average. In 41.2 per cent of cases their closest friend lives in the same household, building or neighbourhood. In contrast, the average household income of people who do not provide disability-related help to family members is $47,610. They have 7.5 friends on average. In 59.5 per cent of cases their closest friends live in the same household, building or neighbourhood.

Restrictive criteria also compound the stresses and challenges of caring for a person with disabilities if needed supports and services are not available. For example, for many families respite care gives a much-needed break from care giving responsibilities. It is an essential support service for the maintenance of their physical, mental, social and spiritual well being. Restricted access to respite, or respite that is available on terms that do not fit the family's situation, puts the health and well being of caregivers, people with disabilities and other family members at risk. Among people who provide help to family members because of disability and who indicated on the GSS that respite services would be useful in enabling them to continue providing help, 45 per cent said their health had been affected as a result of helping. Where the need for respite service is not indicated, only 11.9 per cent of those helping family members because of disability said their health had been effected as a result of helping.

Eligibility criteria that limit access of persons with disabilities to generic and disability-specific supports also have repercussions for family members who must then struggle to fill in the gap. This often means additional expenditures of time, energy and money for family members to deal with the problematic situation itself, and to make direct provision of the support or services which are not available from generic and specialised sources.

Family members consulted during the research called for a family-centred approach to supports and services that respects the needs of people with disabilities and those of their family.

3. Adequacy of family supports — in-home, community and employment-related according to identified need

Strong social support networks involving families, friends and communities are associated with good health. Family supports are especially critical for families during the initial shock encountered upon diagnosis of their child's disability and the tremendous stresses on the families following diagnosis. During these times, families often have difficulty providing the support children need, despite their best efforts.

Unless social support networks are available to assist families during these times, children with disabilities, their parents and their siblings are put at risk, with repercussions to their health and overall development. Siblings undergo tremendous stress associated with the diagnosis and care of a child with disabilities. Feelings and expressions of guilt, anger and jealousy are common. Parents under stress may experience difficulty in dealing with these powerful emotions. Yet, families are often given no referrals to services and agencies that might support them through this very difficult time and assist them in meeting the needs of their children.

Given the increased time, cost and energy associated with providing support to family members with disabilities, supports and services are needed to keep families healthy and able to provide support and nurture, and to participate actively in the life of their communities.

One of the most critical needs is around paid employment. Focus group respondents cited lack of flex time, inadequate parental leave provisions and benefits that recognise care giving responsibilities as key issues. Without these measures, many family care providers experience detrimental costs to their paid work activities. For example, in the GSS a significant share of people who help family members because of disability say that providing help had affected their employment situation in a variety of ways. They reported that they had:

- changed their hours of work (20.3 per cent — 322,000 people)
- come late to work or left early (34.5 per cent (544,000 people)
- missed a day or more of work (31.2 per cent — 491,000 people)
- turned down a job offer (4.2 per cent — 67,000 people)
- affected their job performance (16.0 per cent — 251,000 people).

A significant share of people who help family members because of disability (12.2 per cent or 274,000 people) indicate that having access to flexible work/study arrangements would be helpful in enabling them to continue providing help.

The difficult challenges involved in providing help increase with the number of people whom respondents help because of disability (**Table 23**).

4. Cost to families

Families largely finance the additional costs typically associated with caring for members with disabilities, severely straining family budgets. These costs include: full-or part-time in-home attendant or nursing care; respite care; prescription and non-prescription drugs; adaptive equipment and technology; special foods, clothing and medical and non-medical supplies; renovations and home modifications; adapted vehicles, special transportation or taxi services; transportation, hotel and meal costs

Table 23. Selected impacts of helping family members because of disability and measures that would be helpful, by number of people who respondents help (GSS)

	Resp. helps 1 person		Resp. helps 2 + people	
	% of people who help 1 person	Number affected who help 1 person	% of people who help 2 or more people	Number affected who help 2 or more people
Have extra expenses	47.0%	351,000	47.4%	703,000
Health has been affected	20.2%	146,000	27.0%	398,000
Came late/left early from work	34.9%	159,000	34.4%	385,000
Missed a day or more of work	30.7%	140,000	31.4%	352,000
Job performance affected	16.3%	74,000	15.8%	177,000
Changed hours of work	20.1%	92,000	20.4%	230,000
Flexible work/study would help	9.6%	73,000	13.4%	207,000
Financial compensation would help	12.1%	90,000	18.1%	268,000
Occasional relief would help	15.3%	116,000	17.2%	257,000

for medical appointments with specialists, child care for siblings during medical appointments and emergencies.

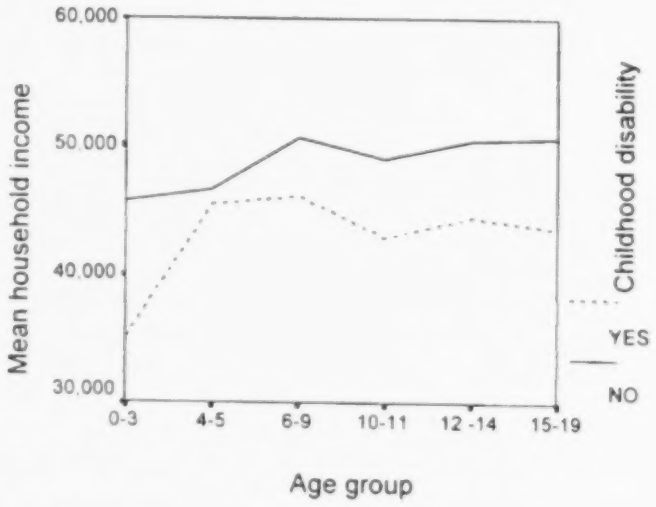
Yet, many families caring for a person with disabilities do not have sufficient income to make these purchases, nor to provide for the optimal health and development of their family members. In fact, children with disabilities are more likely to be poor than are other children in Canada[5], and the general profile of adults with disabilities provided earlier in this reports makes the point that they and their families, too, tend to be poorer than others. The lower family incomes are because in many instances one or more family members (e.g., mother, daughter, spouse) remain out of the paid workforce to provide care, and because inflexible workplace practices make it difficult for family members to maintain a secure attachment to the paid labour force. In many cases, and in particular for single-parent families, this can mean being stigmatised and living on social assistance, well below the poverty line.

Data from the GSS reflect the cost-demands on family members:

- While income from employment is the main income source for most people who provide help to a family member with a disability (70.5 per cent), their earnings are, on average, about $1,400 per year lower than the earnings of people who do not provide such help.
- Total household incomes from all sources are lower in households where one or more children have disabilities than where the children do not have disabilities (**Figure 14**).
- As well, 46.1 per cent of those who help family members have extra expenses as a result (1.077 million people). Taken as a whole, 17.4 per cent of those who help family members say that financial compensation would be useful in enabling them to continue providing help (about 187,000 people); 28 per cent among those with additional expenses say that financial compensation would be helpful.

In a review of the literature The Roeher Institute found that costs related to the care of persons with disabilities or activity limitations are concentrated in two major areas. The first involves direct, out-of-pocket costs that are paid to supplement formal care provided by health, welfare and social service agencies. The second is the cost in lost wages that results from inhibited labour force participation of caregivers of children and adults with disabilities. The breadth of this issue is shown through the following statistics:

Figure 14. Average household incomes where children do/do not have disabilities



Source: The Roeher Institute based on NPHS 1996-97

Direct Economic Costs

Families caring for a child or other relative with a disability face a number direct costs, owing to inadequate amounts of care provided by formal service systems in the majority of cases. A number of recent studies have focused on the effects and costs of informal caregiving.

- While studies regarding the economic value of caregiving have not been conducted in Canada, the cost of informal caregiving to seniors in the United States has been estimated at almost $200 billion (Arno et. al., 1999).
- In a recent U.S. study, Lukemeyer et al (2000) found that almost 50% of low-income families of children with disabilities incurred out-of-pocket expenses, with 20% spending over $150 (Cdn) per month. During the survey, 12.5% of respondents made at least one major purchase over $150 (Cdn). The majority of purchases were related to medical care or special equipment.
- The Metropolitan Life Insurance Company (1999) has estimated that the average caregiver spends over $30,000 (Cdn) on out-of-pocket expenses, over an average caregiving period of between two and six years.
- The economic effects of disability are significant: Twenty-eight per cent of families with children who have a disability find themselves at the lower end of the income scale compared with 17% of families who do not have a child with a disability. Poor children are more than two and one half times as likely to have a problem with hearing, vision, mobility or speech when compared to children in high-income families. Seventeen per cent of children with disabilities are members of families who receive government income support, compared with 8% of children without disabilities (The Roeher Institute, 2000a).

Indirect / Workforce-Related Costs

- Care giving duties are balanced with paid employment and unpaid household-related work for 75% of women care providers, (Montgomery & Kosloski, 2000).

- Estimated annual earnings lost as a result of care-related non-participation in the paid workforce average between $2,338 and $ 7,253 (Cdn) (Jacobs & McDermott, 1989).
- The Metropolitan Life Insurance Company (1999) estimates the average care-related individual lifetime loss of income at $659,139 (US).
- Caregivers may give up paid work-related promotions, relocations, full time work or work altogether to provide care for a family member. This can result in career interruption, time lost from paid work, and financial hardship, leading not only to depressed financial status in the short term, but also to low pensions and benefits in old age (Armstrong & Kits, 2001).
- Full-time paid work is less likely to provide a private pension for women than for men. Non-standard work is unlikely to provide any benefits whatsoever. Many of the women who care for elderly persons – many of whom have disabilities — are engaged in this type of paid employment, and as a result have only public pensions (Townson & Canadian Advisory Council on the Status of Women, 1995).
- In British Columbia, 44% of all women aged 25 to 54 who worked for pay part-time in 1999 did so because of personal responsibilities related to personal illness or disability, caring for children, or taking care of an elderly relative (BC Ministry of Advanced Education, 2000).
- Caregiving responsibilities often preclude paid employment. The lower workforce earning potential and status of women leads to a higher likelihood that more women than men will give up paid employment to provide care. This situation is exacerbated by the scarcity of jobs that allow women to take paid leave to provide care (Statistics Canada, 2000).
- A recent Canadian study found that among 64% of the two-parent families with a child with a disability surveyed, one parent either lost or gave up a paid job to provide supports for their child (Irwin & Lero, 1997).
- The higher cost of substitute care for children with special needs may further limit a woman's choice to enter or remain in the paid workforce (Ibid., Lukemeyer et. al., 2000).

Needed Backup Supports

The Canadian Association of Family Resource Centres (2000) outlined a number of supports that would be helpful to families caring for a child or relative with a disability. These include:

- Parent/caregiver education and support
- Child care and children's programs
- Health education and care
- Youth programs
- Employment support

Existing formal supports can do more to lessen the burden of informal caregiving. These include supports such as: respite, home, and nursing care; direct payments to persons with disabilities; increased paid parental leave from the workforce; and

services such as professional co-ordination, case management and education (Roeher Institute, 2001a, 2000c; Ontario Roundtable on Individualised Funding, 2000; Torjman, 2000; Kagan, 2000).

Following from interviews with parents of children with disabilities in Canada, The Roeher Institute (2000b) outlined a number of supports requested by those in the caregiving role:

- An income support system that takes into consideration the true cost of raising a child with a disability
- Transitional aids for parents who wish to continue education or re-enter the paid workforce after periods of unemployment or receipt of social assistance. This involves the presence of adequate childcare and supportive workplace policies
- Assistance in obtaining appropriate, affordable, accessible housing
- Provision of affordable, high quality inclusive childcare, especially for single parents. This includes the provision of intensive early childhood education and childcare that can accommodate older children who still need support
- A renewed commitment to inclusive education for children with disabilities
- Access to a range of services such as respite care and various forms of therapy (e.g. occupational, physical, speech-language)
- Advocacy and information supports — parents were found to spend a disproportionate amount of time advocating for needed supports and managing and monitoring professional services. A need was expressed for a central source of information, planning and co-ordination services, and proper training for formal caregivers.

5. Cumulative impacts

Appendix Table 10 shows that people who help family members and who themselves need support in order to continue helping are more likely than others to report that personal health is only fair or poor, and that they have a disability themselves. Those with disabilities became disabled earlier in life than is the case among the adult population more generally. Compared with other Canadian adults, family members who provide help and who need extra support are less likely to have recently received income from the Canada or Quebec Pension Plan, perhaps because they were less able to make the required financial contributions to the Plan. Those needing support are more likely than others to experience adverse employment impacts (e.g., missed work, came late or left early, declined a promotion or job offer). They are also more likely to wish that someone would take over helping, that respite was available, and that financial recognition, flexible work/study arrangements and various other measures were available so they can continue helping.

D. Policy Issues For Communities

A key finding of the research was that at the community level there are inadequate resources for the disability sector. This has led to a shortage of trained voluntary and paid disability specialists, to delays and gaps in the availability and delivery of supports and services and accessible community infrastructures, and to a lack of

capacity of local NGOs to engage in disability-related work. Respondents from provincial/territorial ministries of social service were aware of the impact this had on people with disabilities and their families, but stressed that the lack of resources hindered provincial/territorial governments' capacity to provide the much-needed supports. They spoke about the importance of a federal investment in the disability sector if any headway was to be made at the community level.

1. Inclusiveness of mainstream community services — recreation, school, workplace, health care, transportation, etc.

Mainstream community-based programs and opportunities that might facilitate the participation of many people with disabilities, are in many instances not available, located too far away to be useful in any practical sense, or require reliance on inadequate transportation. Where people can get to these generic services, in many cases the services are inaccessible, unaffordable or unresponsive to need (**Tables 7 to 11**).

Difficulties in accessing mainstream services begin almost from birth. In many instances childcare centres can not or will not accommodate a child with disabilities. Often, there are no trained specialists to work with "special needs" infants and children. Fortunately, in a few jurisdictions, money invested by the federal government through the Early Childhood Development Initiative (ECDI) is being used to train and hire specialists and to develop inclusive programming in childcare centres. These initiatives are being looked at as models for further mainstreaming efforts.

The research also collected many stories about the failure of mainstream schools to welcome and include children with disabilities. Respondents cited the need for more flexibility and less stringent parameters for "at risk" children with less demarcation by old standards of mild, moderate, severe disability. They described how teachers sometimes fear the unknown and often over-react if a "helper" is not available for a given child with a disability. Parents, too, are afraid from listening to the "horror stories" of other parents about failed mainstreaming efforts. They will often veer towards special schools or classes without being fully informed about the pro's and cons of all potential directions in education.

People with disabilities and parents described the many restrictions that keep children with disabilities from participating in extracurricular activities (e.g., sports, field trips, and anything that involves accessible transportation). They also reported that there was limited or no access to high school co-op and work experience programs. Students were often streamed into segregated training and work options and short-term programs with little follow-up. Criteria of success tied to independent employability prevent young people for whom this will never be possible from participating. In other cases students with disabilities are streamed into co-op work placements earlier than other young people as a way of removing them from the classroom.

Government officials in several jurisdictions reported that insufficient financial and human resources resulted in situations where no specialists were available in schools to assist sight-impaired and deaf, deafened and hard-of-hearing children, necessitating their removal to residential schools outside of their communities. In other cases, there was no money to hire teaching assistants resulting in children with disabilities not attending school at all. Faced with these issues, parents who have the

means increasingly are turning to distance education or home schooling for their children. Those programs have the advantage of being more flexible than classroom-based education, but isolate children from age peers.

If services and programs are available to people with disabilities, it does not follow that these will include both persons with and without disabilities or will foster the inclusion of people with disabilities more generally in society. For example, parents expressed their frustration with a system that sometimes results in having Teaching Assistants (TAs) do babysitting and manage exclusion rather than facilitating inclusion. They also reported that funding cuts in education have resulted in fewer school-based resources to assist with friendship development, educational planning, and inclusive rather than segregated educational placements.

There is also a sense at the college level that certain groups of people with disabilities (e.g., intellectual disability) will simply not be going to college. There are programs such as those at Humber College in Ontario, the On Campus program at the University of Alberta and at the University of Prince Edward Island and some community colleges that have made efforts to include people with intellectual disabilities, but these programs are very much the exception. Few college or university programs have made any provision to include and accommodate people with intellectual disabilities (The Roeher Institute, 1996) . A recent report from the National Education Association of Disabled Students found that multiple barriers continue to thwart the participation of people with disabilities seeking to further their education at the post-secondary level (Hubka and Killean,1996).[6]

If persons do manage to secure access to college and other programs beyond high school, questions remain as to who is responsible for funding-needed supports. Is this the responsibility of the college / university out of their operational budget? Should publicly-funded supports instead be delivered through ministries responsible for community services, or under ministries responsible for health, or for vocational rehabilitation, or for programs responsible for aids / devices? These questions have not been systematically addressed across the country.

Furthermore, it is very much in question who will fund and take responsibility for the "soft supports" that would help persons orient and adjust to college/university life and to the community beyond. Is this the responsibility of the college/university, or that of community agencies in the disability sector, or the responsibility of government social workers? While some people and institutions are trying to come to terms with these issues, there are no clear, broad-scale answers to these questions.

If access to post-secondary institutions or workplaces is generally problematic for people with disabilities, their successful inclusion in recreation, school and workplaces can be even more difficult without adequate supports and services. Present data do not enable analysis of the extent to which the lack of access to needed supports causes exclusion. However, data provided in **Table 24** do show the extent to which people needing various work-related supports are employed. The depressed rates of employment among people needing various supports in the workplace reinforces the common sense notion that, where such supports are not available, people will have difficulty participating in the workplace — or in other community situations for that matter.

Table 25 provides further reinforcement. It shows a fairly consistent pattern of people feeling that they are under-utilising their skills, education and experience when needed job accommodations are not available.

Table 24. Job accommodations needed by working-age people with disabilities, showing numbers needing, numbers receiving support(s) in workplace and employment rates among those needing/not needing job supports (HALS 1991)

	Employed		Unemployed	Not in labour force	Employment rate
	Need sup't	Sup't avail.	Need sup't	Need sup't	Need sup't
Human support	21,000	11,000	5,000	52,000	27%
Technical aids	18,000	7,000	3,000	20,000	44%
Communication services	13,000	*3,000	*4,000	19,000	36%
Job redesign	100,000	64,000	40,000	248,000	26%
Modified or reduced hours	90,000	57,000	34,000	308,000	21%
Accessible transportation	30,000	15,000	12,000	127,000	18%
Other non-architectural	35,000	18,000	7,000	42,000	42%
Handrails and/or ramps	22,000	16,000	7,000	81,000	20%
Appropriate parking	24,000	16,000	9,000	83,000	21%
Accessible elevator	24,000	16,000	11,000	104,000	17%
Accessible workstation	22,000	15,000	11,000	92,000	18%
Accessible washroom	20,000	15,000	8,000	75,000	19%
Other	12,000	*6,000	—	17,000	39%
Not specified	18,000		11,000	78,000	17%
Any accommodation req'd	208,000		70,000	451,000	29%
Accommodation not req'd	898,345		156,790	614,010	54%
Total employed	**1,106,205**		**186,300**	**1,064,630**	**47%**

*Small sample size. Use figures with caution.

All focus groups reported that generic systems (e.g., recreation, education, training) have difficulty addressing issues of disability and enabling people to access supports from specialised sources if necessary (e.g., physiotherapy, psychiatric services). The capacity of generic systems and programs to include and support people with disabilities needs to be strengthened.

This would include designing new facilities and programmes that from the outset enable inclusion, and providing adaptations to existing facilities and programmes to remove barriers to participation. It would also involve educating staff to recognise and eliminate biases in policies, programmes and services that result in the under-representation, marginalisation and/or exclusion of persons with disabilities and to identify and challenge pervasive and deeply established social attitudes, conditions and behaviours that contribute to these biases.

Lack of community resources such as accessible transportation results in problems for people with disabilities to access other community services such as health care, recreation and social activities. Measures need to be put into place to ensure that community public transportation services are accessible. Some communities are

moving in this direction and have adopted a policy of ensuring that all new transportation vehicles purchased are barrier-free. This would reduce the dependency on specialised transportation by people with disabilities, a system currently fraught with difficulties in many communities, and would accord people more equal access to regularly scheduled public transportation. In turn, better access to regular transportation would bring people with disabilities more fully and clearly into the mainstream, helping to sensitise others to their needs and to their presence in the community.

While living in northern, remote and rural locations may make access to community services difficult for anyone, transportation issues further disadvantage people with disabilities. In some jurisdictions where access to services from remote locations is only by aeroplane, costs associated with transportation for a person with disabilities and their attendant are prohibitive. Senior government officials in several jurisdictions raised this as a daunting issue for which assistance from federal investments would be welcome. Travel for attendants on long-haul buses and on trains is currently free in Canada. Participants noted that similar arrangements for air travel would reduce the barriers facing those who are dependent on it.

Table 25. Percentages of people whose needs for job accommodations have been met / not met, who feel that they have the opportunity to use all their skills, education or experience in their present job (employed HALS respondents)

	Percentages who feel they are fully using skills, education, and experience	
	Where job accommodations available	Where job accommodations not available
Human support	69.2%	66.8%
Technical aids	75.9%	57.4%*
Communication services	53.1%	72.5%
Job redesign	60.7%	44.7%
Modified or reduced hours	57.1%	53.3%
Accessible transportation	65.1%	54.5%
Other non-architectural	57.3%	55.9%
Handrails and/or ramps	65.9%	55.0%*
Appropriate parking	63.2%	49.7%
Accessible elevator	71.8%	67.1%
Accessible workstation	62.2%	56.6%*

* Small sample sizes. Data within release guidelines but should be used with caution.

2. Accountability for full citizenship and inclusion by community sectors and governments

There was agreement among respondents across the country that accountability mechanisms largely serve system-based case management, instead of people with disabilities and their families, resulting in unmet needs. Respondents cited the need for outcome measures to assess how well the needs of people with disabilities are being met and how well systems are functioning to serve those needs. They are asking for planning, co-ordination and other services that are accountable to people with disabilities and to their families.

While efforts to include accountability frameworks in a new FPT initiatives were applauded, concerns were raised that measures developed may not be inclusive of people with disabilities. For example, under the National Children's Agenda (NCA), which applies to all children, both levels of government have made considerable commitment and given a sense of urgency to developing an adequate reporting and

accountability framework. *In Unison* makes no reference to children or families; while it refers to the need for monitoring and accountability, concrete monitoring arrangements have been slow to be set in place.

Governments are busy setting up reporting systems for the recently launched Early Childhood Development Initiative (ECDI), one of the first initiatives under the NCA. While the reporting under the ECDI will focus on the national and provincial/territorial level, there are concerns about some community-level data. Parents of children with disabilities expressed grave concern about the potential for these systems to exclude their children. Some community-level social mapping initiatives underway that could feed into these reporting systems, for example, have examined the relationship between quality pre-school programs and the socio-economic assets of the communities. Maps have been produced, but the small print reveals that special needs students have been excluded from the data collection exercise. Ready-to-learn criteria, another much-discussed measure in background documents of the ECDI and NCA, expressly exclude many children who because of their disability may never meet the targeted 'age-appropriate' motor, social and academic skills. Respondents are asking for bias-free indicators that do not result in disability being equated with failure and deficit, and are calling for indicators of success that are inclusive of all children.

Concerns were also raised about the difficulties of setting common standards and monitoring for successful outcomes in the context of regionalisation. For example, how will provincial/territorial governments measure what outcomes are actually achieved with special education dollars? Parents cited the frustration of not having supports and services accountable to families at the school level. They explained that funding for special needs education flows to school districts and boards without monitoring or clear accountability for inclusive outcomes.

In some jurisdictions there was concern that special education dollars were not actually spent by schools on educational services for children with disabilities. Examples were given of teaching assistants (TAs) being used for yard duty at lunchtime, to give teachers a break. As a result, the TAs did not have time to prepare adapted classroom materials for use by students with disabilities, hindering their inclusion within mainstream instruction. Parents also expressed their frustration with a system that leaves them without recourse when special education in segregated class is presented as the only educational option available to children with disabilities.

Adults with disabilities expressed how they felt trapped within a system that they perceive as being accountable to no one. Some described how they were given no options but to work in sheltered workshops and receive what they considered to be 'slave-wages'. They reported that no one was accountable for monitoring their on-going development as people, and their changing needs, skills and aptitudes. They spoke about the hampering of their rights to make choices about their career options and to fulfil their dreams. Others spoke about the lack of accountability of specialised services to their needs and the lack of recourse where the level or quality of service available was at issue.

Concerning various approaches to ensuring accountability, senior provincial officials who were interviewed raised concerns about the potential burden of reporting and accountability measures, especially in smaller, under-resourced jurisdictions. While acknowledging the need to be accountable to the disability community and to the Canadian public more generally, officials expressed concerns about any national reporting system unless federal monies were transferred directly to provinces and territories to assist in this monitoring activity.

3. Investment in human resource development in the disability support sector, for training, education, wages and benefits, labour market development, collective bargaining arrangements

A range of human resources and professional development issues requires attention for building inclusive generic services that are supportive of people with disabilities. Education and training are urgently needed to improve the understanding of disability-specific issues and to challenge negative and stereotypical attitudes and perceptions of disability.

For example, aside from course work specific to biomedical treatment issues (e.g., neurology), physicians and other health professionals may receive little in the way of formal training on general life issues for people with disabilities. Focus group respondents reported the view that little is being done in medical and nursing schools to raise awareness about the issues children and adults with disabilities face, and the implications for families. Across focus group sites, respondents consistently reported difficulties with health professionals who seemed to have little information about alternative support arrangements to traditional medical services. In the absence of such information, participants reported how professional practice results in the prescription of overly medicalised service arrangements and a failure to refer individuals and families to other community options. The need for new approaches to planning involving health professionals and other stakeholders, including families, has been addressed in other Institute research (The Roeher Institute, 2000).

Class-room teachers, post-secondary educators, recreation leaders and job trainers typically receive little if any professional development on accommodating curricula and teaching practices to the needs of students with various learning styles, health issues, and functional limitations.

Employers typically have little understanding of disability issues or the potential contributions that people with disabilities can make to the workplace. Nor, as a general rule, do employers and human resources professionals have much background on job accommodation possibilities and processes. At the same time, funding is scarce for community organisations in the disability sector to provide employers and human resources professionals with awareness raising and consultations on these issues.

Government officials raised this as a key issue.

Furthermore, lack of funding for NGOs in the disability sector precludes much-needed training for agency staff and volunteers in recreation and other sectors, severely restricting the capacity of NGOs in the disability sector to deliver supports and services to the community at large.

Through the efforts of community, provincial and some national organisations in the disability sector, police, lawyers and members of the judiciary are gaining increased understanding of disability and disability-support issues in the criminal justice system. Significant efforts continue to be needed to advance awareness and competencies in the criminal justice system.

Even for employees working in disability-specific service agencies, training is an issue. People working in the sector may have received college training in human service worker programs, but this is not always the case. That training may not be pertinent given the changing understandings of disability that have taken place in the past decade, and the new expectations and new challenges that need to be

addressed. In-service training for employees of community agencies is sporadic and typically not well funded.

During the focus groups, respondents expressed frustration with professionals who, when faced with the prospects of having to deal with a person with disabilities, are heard to say, "I wasn't trained for this". Respondents explained that they also were not trained, but that they learned in a hurry because they valued their family members with disabilities. They looked forward to a society that acknowledges and values the many kinds of people within it, and stressed that willingness and openness is more important than formal training. However, they also cited the need for:

- Disability awareness to increase respect for and dignity of persons with disabilities and their families and to remove some of the obstacles to community living/independent living, including a Ministerial awareness campaign targeted to service providers and the general public
- Workers to listen to the needs of the parents/families
- Workers to be kept up to date on services available outside their specific area of expertise
- Training for families to prepare for transitions, including financial planning and co-ordination, and for quality of life for the future
- Disability Training such as the "Defils" Program in Laval
- Up-to-date, latest "best practices" examples for training sessions for service providers as many workers were felt to still have archaic methods, language and attitudes. This would include workers in child care/after school care, teachers, teaching assistants, school principals, school counsellors, physicians, other health care professionals, social workers, counsellors, etc. The AQIS Training Program in Quebec, for example, was cited as an excellent example of best practice model.
- Sensitivity training and group work with parents, workers, planners, government, etc.,
- Co-ordinated disability training for police fire, drivers, parents, service providers, workers, teachers, day care providers, etc.
- Summer Institutes for continuous training for educators who may fear change and difference, or who may be confused about their job descriptions and roles.
- Awareness raising and training to transform perceptions among professionals working in adult services whom in some instances continue to view adults with disabilities as children.

Community education programmes are needed at a broader level to educate the public, professionals, and the media concerning the principles of equality, respect for diversity, fairness, individual dignity and responsibility, and mutual aid and responsibilities for one another. Such programmes could also give people the skills needed to recognise biases that lead to the exclusion, marginalisation or objectification of any person. Education programmes are also needed to challenge and change pervasive and deeply established social attitudes and behaviours that contribute to these biases.

Staff turnover in the disability services sector is high and wages are modest. Without better supports and working conditions, there will continue to be a problem attracting dedicated people to work in the sector.

Demographics, low unemployment rates and volunteer exhaustion contribute to staff shortages. The ageing of both paid and unpaid workers and of the population of people with disabilities has brought about a decrease in the supply of workers and an increase in the demand for services; with age, the incidence and severity of disability increases. For jurisdictions struggling with limited resources that are not keeping pace with inflation and rising costs, the situation is becoming quite acute. Without more money invested, their capacity to deal with staffing issues is severely restricted.

Several jurisdictions reported that staff shortages mean that certain services just are not available within some communities. They cited a lack of trained, qualified specialist teachers for sight-impaired and deaf, deafened and hard of hearing students, lack of speech pathologists, occupational therapists and physiotherapists, especially in northern, remote and rural locations. They reported waiting lists for respite and attendant services, for rehabilitation and planning services, for child care centres, for supported living and residential support. One jurisdiction reported a one academic-year wait list for university-based services. In several jurisdictions, thanks to money invested in the ECD Initiative, there were reports of no waiting lists for children's services. The ECDI is being held up as a successful model for investments in the disability sector.

Staffing issues are also hampering movement towards individualised funding models. Much work remains to be done to develop fair and respectful hiring and human resource management practices for those working directly with persons with disabilities or their families.

The devaluing and disenfranchisement of people with disabilities and the overload on their families has contributed to this situation. It has also had a detrimental effect on community-based service providers. For example, the low value accorded people with disabilities has been translated into low value placed on paid work within the sector. Thus, wages and benefits are low; there are wide pay differentials between those working in institutions and those in the community; and staff, particularly if they are not unionised, are in a weak collective bargaining position. As discussed earlier in this report, the situation of informal caregivers is even more precarious, in that their work is often unrecognised. Much work remains to be done to develop and sustain the human resources in the disability sector if people with disabilities are to exercise their full citizenship.

Many jurisdictions recognised that the low value placed on the disability sector has contributed to its lack of funding. They stressed that efforts are needed to raise the profile of the disability sector. However, government officials found that engaging the disability community is difficult, as officials perceived it to be disorganised and fractured. Several issues are involved. For many people with disabilities, and for their families, tremendous time and energy are taken up just trying to cope with every day tasks and issues, leaving little time for participation in outside activities or organisations. Costs are another issue, both for persons and for organisations. Many persons with disabilities and their families can not afford the extra costs associated with attending meetings; child-care expenses, transportation costs, and membership costs can be prohibitive for many persons and families, given the other costs they also face.

As well, disability organisations, like most NGOs in the country, are not well endowed. Many focus their resources on providing supports and services to their members and do not have sufficient resources for linking with other organisations or groups. National disability organisations need funding to build capacity at the

provincial level to engage in work at the local community level. Investments in national disability organisations are needed to assist this process. An initiative led by senior representatives of federal and provincial/territorial governments could act as a catalyst for bringing disability organisations together to tackle issues they have in common and which present challenges to all levels of government.

4. Strategy for the deinstitutionalisation of people with disabilities

Generally, there is not a proactive, systematic, wide-scale strategy to move people from institutions to the community and to reinvest in needed supports for people with disabilities who want to resume their lives in the community. Even in jurisdictions that have made significant progress in the past decade to help people move to the community (e.g., Ontario, British Columbia), pressures have reportedly emerged to institutionalise people.

Several jurisdictions reported an increased demand for costly residential services, particularly for those living with FAS/FAE and related drug and alcohol problems and for other people at high risk of criminal offences. In some jurisdictions, funding of drug and alcohol treatment and FAS/FAE prevention programming takes up the bulk of available monies, leaving little for deinstitutionalisation efforts and other disability support programmes.

To facilitate the community inclusion process, there is need for funding and for knowledge and skills transfer. There is also a need to move from overly medicalised support arrangements (e.g., full-time, facility-based nursing) to less medicalised, community-based options that effectively meet needs. While progress is being made in some jurisdictions and particular situations to further this transfer of knowledge and skills, the progress is neither systematic nor wide-scale across Canada.

There is also a need for affordable, supported housing in the community if independent living is to be a viable option. Supported housing is reportedly becoming very difficult to obtain for young people. As a result, young people are being required to stay within the family home or to obtain institutional placement in nursing homes and other facilities. An example is that of a daughter who cannot get supported housing and whose mother planned to move out of the family home to rent an apartment so the daughter could live independently with secure housing in the environment she knows. As the family home does not meet licensing standards for paid support workers (e.g., inadequate fire exits), support workers are not available to the young woman in the family home. A life of greater independence has been thwarted as a result.

Funding arrangements tend to favour congregate living (special care homes, nursing homes, large group homes). In some jurisdictions wings are being attached to nursing homes specifically designated for people with disabilities. However, population data (Statistics Canada, 1994: Table 3.10) show little demand in the disability community for congregate living. In total, fewer than 10,000 people 15 and older with disabilities preferred to live in group homes or boarding, rooming or lodging homes in 1991. Research shows much higher levels of social and economic inclusion where persons have access to self-managed and self-directed support in their own home (The Roeher Institute, 1997).

The Residential Rehabilitation Assistance Program (RRAP) for Persons with Disabilities provides loans that can be used to render dwellings accessible to people

with various disabilities. For homeowners, the program is income tested and the value of the home must fall below a specified figure. Landlords may be eligible if the rents are below established levels and the units are occupied by people with incomes below specified income ceilings. Rooming houses that meet rent criteria and minimum health and safety standards may also be eligible. The maximum loans available are worth between $18,000 and $27,000, depending on region of the country. For homeowners, there is a forgivable component to the loans, which varies from a maximum of $12,000 to $18,000, depending on region. Total household income and the cost of modifications are also taken into account in assessing the forgivable amount for homeowners. Homeowners may be eligible for additional assistance. While this has been a useful program for many people, those who do not meet the eligibility criteria or who feel that they cannot carry the loan would have to pay out of pocket for the needed home modifications, or turn to charities for financial assistance.

Social assistance is not keeping pace with rising rents, making it difficult for people to make the transition from their parents' home to greater independence. Current data on rents in Canada are not available. However, the following table (**Table 26**) shows the maximum allowable welfare income for single persons with disabilities in Canada in 1999, the average cost of housing across the provinces that year (rental and owned), and an estimate of average rental costs. These are based on 1996 Census data and the cost of living increases (provincial, for shelter) since the Census. Average rental costs come near to consuming — and in two jurisdictions exceed — maximum allowable welfare rates for people with disabilities. Such figures do not take into account the cost of utilities, furniture, food, clothing, other basic necessities and disability-specific costs.

Table 26. Average shelter and welfare amounts for persons with disabilities, 1999

	Avg. cost of shelter (rented and owned)	Avg. annual rental in 1996	Consumer Price Index increase (1999/1996)	Est. average annual rental based on Census and CPI data	Maximum welfare rates for single persons with disabilities	Avg. rental as % of welfare
Newfoundland	$6,691	$6,168	1.03	$6,327	$8,480	73%
Prince Edward Island	$7,985	$6,624	0.97	$6,458	$8,208	81%
Nova Scotia	$8,197	$6,864	1.02	$7,029	$8,568	80%
New Brunswick	$7,513	$5,796	1.04	$6,035	$6,696	87%
Quebec	$8,241	$6,540	1.02	$6,684	$8,712	75%
Ontario	$12,038	$9,012	1.02	$9,224	$11,466	79%
Manitoba	$8,601	$6,360	1.05	$6,661	$8,027	79%
Saskatchewan	$7,839	$5,988	1.06	$6,344	$8,160	73%
Alberta	$10,349	$7,320	1.07	$7,802	$6,858	107%
British Columbia	$11,551	$9,540	0.96	$9,175	$9,337	102%

Sources: Statistics Canada 1996; Statistics Canada 1999; Statistics Canada CANSIM; National Council on Welfare (Autumn 2000). Welfare Incomes 1999. Table 5.

Depending on the jurisdiction, social assistance may not encourage rent sharing; welfare income may be lost when people live together and share rent. The value of the informal assistance provided by a housemate to a person with a disability is not acknowledged by the social assistance system. The lack of in-home supports from the community system to persons with disabilities in these situations is resulting in strain on relationships and living situations that are falling apart.

Challenges in obtaining affordable housing and the needed supports, result in persons with disabilities typically having to take housing where the supports are available (e.g., group homes and other congregate living arrangements where a measure of formal support is available). However, focus group participants reported that budgets for such arrangements have been capped. Service agencies that provide such living arrangements are shifting attention to people on waiting lists who have low level, predictable needs and who do not require major investments in agency-based staff support.

---

1. Data are not available for the years between 1993-94 and 1997-98.

2. A relatively small number of working age people (113,000) indicate that they need help with everyday activities but get none. These people have been excluded from Table 22. Compared with others who need help with everyday activities, they tend to have less severe disabilities, to be better educated, better attached to employment and less in need of any job accommodations. Overall, their need for support seems to be less significant than that of others with disabilities who need support.

3. Based on HALS, the research found that 89,000 adults with disabilities have all the help they need with everyday activities, were helped by community service agencies and either did not pay for the services they receive or were fully reimbursed for their out-of-pocket payments. This works out to 4.8 per cent of the 1.854 million adults with disabilities who needed support with everyday activities, and 2.5 per cent of adults with disabilities taken as a whole. Some 43,000 of the 89,000 (2.3 per cent of all adults with disabilities needing help with everyday activities) were helped exclusively by community services and had their needs fully met at no net cost to themselves. That is, family members, friends and neighbours were not involved in providing assistance in those cases. Unfortunately, HALS data are not available on the amounts that people pay for community services to assist with everyday activities.

4. See *Beyond the Limits: Mothers Caring for Children with Disabilities*, The Roeher Institute, 2000.

5. The Roeher Institute, *Count Us In: A Demographic Overview of Childhood and Disability in Canada*, Toronto, 2000.

6. *Employment opportunities for post-secondary students and graduates with disabilities: A National Study*

Context for Addressing the Policy Issues

Researchers heard a consistent message from focus groups across the country: without adequate supports and services, particularly around transition points, people with disabilities and their families undergo unnecessary hardship and are disenfranchised from full and active participation in the social and economic life of their families, communities and country.

Accounts gathered during the consultations with people with disabilities, their families, service providers and government officials are supported by data from major national statistical surveys. Data show that, persons with disabilities and their families are experiencing high levels of stress, hardship and exclusion. Compared to people who have no need of help or whose needs have been fully met, people with disabilities fare less well across a range of situations where they need more help with everyday activities or aids/devices than is available to them.

The data also show that generic and disability-specific community resources are inadequate to meet existing needs. This inadequacy stems from limited financial resources for the disability support system within communities and from a piecemeal approach to the delivery of supports and services across the country. There is no comprehensive, coordinated, systematic, person- and family-centred system of disability supports identification, planning, co-ordination and delivery. What exists takes place in silos within sectors and jurisdictions. Persons with disabilities and their families negotiate this tangled web largely on their own, and those without the skills, time, energy and resources to manage on their own often fall through the cracks.

In short, there are a multitude of issues with many dimensions that affect people with disabilities, their families and the communities around them. To address these issues, there is a need for a multidimensional, integrated, coordinated and comprehensive policy response across sectors and jurisdictions.

In formulating an effective policy response, it is helpful to take into account current trends in: 1) the federal-provincial/territorial policy environment; 2) jurisprudence on disability supports; 3) trends in service delivery at the community level; and 4) the international policy context for disability supports.

The following discussion provides a summary of principles and directions drawn from research and reviews in these four areas. A more detailed discussion of trends in each of these four areas is provided in the Appendix.

A. Federalism and the Social Union

Public policy making in Canada has long been made in the context of a sometimes-challenging federalism among the federal and provincial/territorial governments. To move forward on a comprehensive and multi-dimensional policy agenda, clarity about the nature of the intergovernmental regime in which that strategy will be made and delivered is critical. Different intergovernmental regimes have characterised the making of public policy in the disability sector over the past number of decades. Lazar (1998) identifies four types of intergovernmental regimes:

- unilateral federalism where the federal government, without provincial approval, attaches conditions to financial transfers to provincial governments in an area of exclusive provincial jurisdiction;
- 'classical' or disentangled federalism where each order of government acts independently in its areas of constitutional competence; in areas where each has jurisdiction and chooses to exercise it, the two orders of government act independently of each other;
- collaborative federalism where the two orders of government, recognising their interdependence, act jointly with no undue reliance on "carrots or sticks"; and
- inter-provincial collaboration where there is collaboration among provinces with no federal involvement.

Analysis of disability policy according to these regimes suggests that there is a growing disentanglement of responsibilities between the levels of government in the disability sector as in other sectors.

Concerns have been expressed by the disability movement during 1996 hearings for the Federal Task Force on Disability, and by senior provincial/territorial officials in interviews conducted for this study, that disentanglement could go too far. Complete disentanglement of governments in the disability sector would make it extremely difficult to reach widely shared goals for reform, as expressed in In Unison, for example. As well, it would violate the spirit and principles of the Social Union Framework Agreement (SUFA) that commit to partnerships among different levels of government, persons, families, communities, voluntary organisations, business and labour to make and realize social policy goals.

Policy making is further challenged in the disability sector not only because of the relationship between federal and provincial/territorial governments. Recent years have seen an increasing devolution of provincial responsibilities for funding, regulation, and service delivery to local and regional authorities.

A key challenge in constructing an adequate intergovernmental regime to guide and implement policy and services for disability supports is to decide at which stages of the policy-making process collaborative federalism is needed, and at which stages it should become more disentangled. We identify five broad stages of the policy making process that generally reflect various definitions to be found in the policy literature (e.g. Dye 1995, Walt 1994):

- Setting broad policy goals and objectives
- Establishing funding arrangements
- Choosing of policy/program measures
- Program delivery arrangements;
- Monitoring and information collection/dissemination

Analysis of current trends in the federal-provincial/territorial context for policy making in the area of disability supports suggests that the following principles should guide the design of inter-governmental arrangements for an effective policy strategy.

1. Given the wide range of policy issues to be addressed, collaborative arrangements among governments are required to establish joint policy objectives to deliver on the In Unison accord.
2. To ensure development of a coordinated macro policy response, governments need to collaboratively think through the range of tax and direct expenditure measures that could be used to address the issues at hand. Meanwhile, provinces and territories would continue to design their own funding arrangements for an array of services and supports unilaterally so they can meet their own commitments under In Unison. Similarly, the federal government could pursue policy and program reforms using instruments that fall within its jurisdiction (e.g., EI, CPP).
3. A more disentangled, inter-provincial regime is needed in choosing policy/program measures and delivery arrangements to encourage innovation and local responsiveness.
4. A collaborative, federal-provincial/territorial regime is needed at the monitoring and information stage, to facilitate learning from the diverse arrangements, sharing lessons across the country to inform policy making, and for gauging how well the policy strategy is being delivered. Federal-provincial/territorial and inter-provincial/territorial sharing of information specifically on innovations and best practices in supports and services could also be designed with some significant benefit.

B. Jurisprudence and Disability Supports

Developing a comprehensive policy strategy to provide needed disability supports to persons with disabilities and their families should take account of the current legal obligations of governments, beyond statutory law and public policy. For this purpose, the research for this study included a review of primarily Canadian jurisprudence on the subject. A small sample of American cases was also examined because of the direct bearing the cases have on the rights of persons with disabilities, and because of the way in which their reasoning elaborates on that of comparable Canadian cases. The review devoted particular, but not exclusive, attention to case law where persons with disabilities have been directly involved.

The focus of the review was on leading cases that deal with or otherwise define the legal rights of persons with disabilities, particularly the right to access needed support services. Themes explored included the responsibility of the state concerning disadvantage, "best interest", freedom and dignity, the "duty to

accommodate" and addressing needs with finite resources.

Key principles that can be distilled and synthesized from the jurisprudence to guide the design and implementation of a policy strategy for disability supports are as follows:

1. Disability supports, by their nature and definition, should foster full participation, membership, and inclusion.

2. People with disabilities have long been disadvantaged. The state has a responsibility to address that disadvantage with an investment that should not put "too low a value on accommodating the disabled."

3. Human dignity and self-determination should be protected in policy – through investments and provisions that assign to people with disabilities and their families maximum control over how their supports will be provided, and to define for themselves how their 'best interests' will be met.

4. Because of state obligations to safeguard dignity and self-determination, people have a right to live in the community, and the state has a responsibility to support the shift from institutional care to community life.

5. Managing investments in disability supports should ensure that Charter rights to equality are met, and that disparities in level of and access to supports – across communities, and provinces/territories – are addressed, understanding that the state may not be able to meet all needs for support.

Further detail concerning jurisprudence on disability supports in Canada can be found in Appendix C1.

C. Community Supports and Service Delivery Context

The review points to four key issues to be taken into account in developing a policy strategy designed to restructure disability supports and services at the community level (See Appendix C2).

1. There is a need to shift from a traditional community services system that establishes people with disabilities and their families largely as clients, to one that is more empowering and enabling of their full inclusion.

2. To make this shift, a transition is required from a largely supply driven system to a more demand-driven one, where persons and families have more purchasing power and control over the resources of the system, within an accountable policy and program framework.

3. Institutionalised support options need to be addressed, and deinstitutionalisation accelerated. To make this possible both transitional and targeted funding are needed to assist poorer provinces in this regard.

4. Investment in local communities is required to assist local organisations shift from a traditional to a more empowering service system.

5. Mechanisms are needed to gather information about best practices and innovations at the local level, and to share this information across communities and jurisdictions.

D. International Policy Context

A number of policy initiatives in the international context were reviewed to gain a broader information base on how issues of disability supports are being addressed in other countries. The aim of the review was to identify initiatives that addressed emerging policy issues in the Canadian context, that demonstrated a social perspective on disability, and that were consistent with the kinds of policy goals set out in In Unison.

As identified earlier, policy initiatives can be categorized in terms of (1) the effects they have on individuals, (2) the effects they have on families of people with disabilities, and (3) how they enable communities to be more aware and inclusive of the presence of disability. The following discussion outlines various policies in terms of these three categories.

The following sections provide overviews of the initiatives and commentary from key informant interviews. Countries included in the review were the United States, United Kingdom, Italy, Finland, Norway, Australia and Sweden.

A. Policy Initiatives Relevant to Individuals

In order to deal with problems concerning the lack of access to services and supports – whether they be related to living independently, attending school, or participating in the workforce – several countries have either instituted or are considering the institution of direct funding at the national level. For example:

- Italy recently passed a new national law (328) which has the potential to make radical changes to the pattern of services to people with disabilities. In Article 3, paragraph 4, it is stated that direct payments must be the rule, and provision of services the exception. This law requires regional parliaments to pass laws to support the development of direct payments.

There is a growing belief in Italy that individualised funding is tied directly to the right to personal control and freedom, and can therefore be considered a constitutional right of people with disabilities. This belief is supported by the argument that direct funding enables people with disabilities the freedom to choose with whom they spend their time, how their day is structured, and how their body is treated. Since direct funding allows individuals to choose who has access to their selves and their bodies, this form of support increases personal freedom and control. The inability to choose the supports one makes use of is thus seen as unconstitutional. This view has been acknowledged by the national parliament in Law 328.

- While not yet law, the Medicaid Community Attendant Services and Supports Act (MiCASSA)[1] has been proposed in the United States. Supported by over 600 interest groups, this act would establish a national program of community-based attendant services and supports for people with disabilities, regardless of age or type of disability. This would allow individuals or their representatives to choose where and from whom they would receive services and supports. For example, any person entitled to care in a nursing home could choose where and how services are provided. MiCASSA would eliminate Medicaid's bias towards institutional care by assisting states to develop and enhance comprehensive, state-wide, long-term service and support systems which enable increased consumer choice

- Under the program New Tools for System Change, the U.S. Health Care Financing Administration (HCFA)[2] will make available grants totalling up to $8 million in 2001 to support State efforts to improve community-based personal assistance services.
- The HCFA has also promulgated a final rule which aims to remove barriers that prevent States from providing effective health and long term care coverage to selected groups of persons. Section 1902(r)(2) of the Social Security Act can be used to provide effective health coverage under Medicaid to persons with income above the social security limits, but whose medical expenses so erode their income that little is left to pay for personal living expenses.
- In Sweden, two pieces of legislation were passed in 1994 which govern services to people with disabilities, and which reveal a shift towards a more rights-based framework. These are (1) the Act concerning Support and Service for Persons with Certain Functional Impairments (SFS 1993:387, known as LSS); and (2) the Act concerning Compensation for Assistance (SFS 1993:389, known as LASS).

LSS provides the basis for the provision of services which include home-based personal and attendant care, as well as financial support (over and above welfare benefits) to cover the costs of personal services.

LASS deals specifically with personal assistance. Under this provision, financial aid for personal assistance is provided from the National Insurance Funds, through local insurance offices. Assistance is available to people who are under age 65 at the time of application, who require assistance with daily living for more than 20 hours per week, and who are not living in an institution or group home.

Assistance is also provided to children with special needs who require personal assistants in school. There is a legal requirement for schools to hire such services, even when assistance may be needed for less than 20 hours per week.

- In 1996, legislation was passed in England and Wales that removed the prohibition for local authorities to make direct payments to individuals. Thus the mechanism for direct payments was put into place, with accompanying guidance from central government. Provisions have been extended to people over retirement age, and (from this year) to families with children under age 18 who have disabilities.
- The recently-released White Paper indicates that local authorities in the U.K. will be required to provide direct payments to people with disabilities when requested. The value system implicit in the document emphasises the right to independence and empowerment of people with disabilities, although the original policy matched a political agenda to dismantle state social services.
- The U.K. Independent Living Fund (ILF) is a trust available to those eligible for the highest level of disability living benefit (DLA), and who have been assessed as requiring local authority assistance. The fund was set up in 1988 as a mechanism to provide people with disabilities with funds required to obtain personal assistance.

B. Policy Initiatives Relevant to Families

A survey of the social service systems of various countries highlights the gap between what can be done for families who have members with disabilities and

what is currently done in Canada. It is clear that children with disabilities often place a larger than average financial burden upon their families. Several countries, notably Sweden, Finland, the United Kingdom, Norway, Australia and the U.S. have attempted to accommodate these special circumstances.

- In Sweden, parents of children with special needs are allowed up to 120 days per year off work in order to care for their child. During this time they are paid 80% of their income (for those with an income between $1,300 and $43,000 Cdn).[3] A care allowance is also available, which averages approximately $8,500 per year.[4] Also in place is an Assistance Allowance which subsidizes the employment of personal attendants and home care workers[5].
- In Finland, a Child Disability Allowance is in place which pays parents between $100 and $425 Cdn per week, depending on the level of the child's disability. As well, a Special Care Allowance affords parents up to 60 days per year off work to participate in the treatment/rehabilitation of their child[6].
- In the United Kingdom, a Disability Living Allowance is provided for the care of children under 16 years of age[7]. $30 to $120 Cdn per week is provided for care, and $30 to $82 Cdn per week is provided for transportation. In the case of people receiving income support, this money is not deducted from support payments. For those children who require more than 35 hours per week of care, the Invalid Care Allowance (up to $90 Cdn per week depending on income) is provided as a supplement to income support payments[8].
- Norway has a policy of providing financial compensation to those who would be members of the workforce if they were not required to perform caregiving duties to a family member. This policy was instituted to narrow the income gap between men and women, which is often caused by the fact that women perform the majority of informal caregiving duties[9].
- Australia offers a Carer Allowance to those who provide care to a person over 16 years of age who has a 'functional disability,' or a child under the age of 16 who requires 'substantially more care and attention' than a child without a disability. The non-taxable allowance is neither income- nor asset-tested, and is given in recognition of the impact providing care to an individual has on the individual's family. The rate of payment as of July 2001 was $65 Cdn every two weeks[10]. Also available is the Carer Payment, which is aimed at those who are unable to participate in the workforce because of caregiving responsibilities. This program is income-tested, and is meant as a resource for carers with limited means[11].

Australia also provides the Respite for Carers of Young People with Severe or Profound Disabilities program. It is meant to expand respite supports to those who have been unable to access them in the past, as well as to provide increased access to information and other supports needed by family caregivers. It is a program partner in the Staying at Home package, which distinguishes between carers who have been caring for offspring with disabilities for greater or less than thirty years[12].

- The United States contains provisions for family leave under the Family Medical Leave Act (FMLA). Family members are allowed time off for (1) pregnancy and adoption-related care; (2) care for a spouse, son or daughter, or parent with a serious health condition who is incapable of self-care; and (3) the presence of a serious health condition which results in the inability to perform

all, several, or one essential job function. Employees are eligible for 12 work weeks of unpaid leave in a 12 month period. The employer's share of health insurance coverage during leave, and reinstatement of the same or equivalent position upon return is guaranteed. The policy applies to regular and full-time, as well as temporary and part-time employees.

C. Policy Initiatives Relevant to Community-Building

In order for people with disabilities to participate in society at large, it will be necessary to institute various reforms related to the built environment and human infrastructure of communities. Following are some examples of such initiatives in the U.S., U.K., and Sweden.

- Access Housing 2000 is a proposed national program in the U.S. which will make use of housing vouchers, Nursing Home Transition Grants, and Medicaid funds to provide improved access to affordable housing and supportive services for the elderly and people with disabilities[13].
- The U. S. Department of Housing and Urban Development (HUD) is collaborating with the Health Care Financing Administration (HCFA) to assist States (and partnering organisations) in the transition of people from institutional to community settings. Between $12-$15 million will be awarded in State program grants for eligible persons of all ages.
- The HCFA has also instituted a major initiative to promote the design and delivery of community-based services which support persons with disabilities or chronic illnesses to live and participate in their communities. Congress and the HCFA have made $50 million available for this initiative. Funding is aimed at long-te[illegible] services and supports, including attendant care to persons in the most integrated settings appropriate to their needs.
- Sweden has designed the policy statement From Patient to Citizen: a National Action Plan for Disability Policy, which emphasises the need to achieve a social community based on diversity by removing obstacles to full participation, independence and choice for people with disabilities. Policy initiatives include the following:
  - Government agencies are required to integrate a disability perspective into all their operations, and ensure their premises are accessible.
  - Public buildings and places are to be made fully accessible by 2010.
  - Improvements are to be made in the accessibility of public transport systems.
  - There will be resort to legal procedures, including fines, to force local authorities to deliver services to which persons have a right.
  - Public arts funding to favour projects that promote better attitudes towards people with disability.
  - Investigation of the reasons for an increase in the numbers of children attending special schools.
  - Various initiatives to improve access to education, including development of teaching aids and technical aids.
  - An investigation into the personal planning processes already required in law, but recognised to be operating ineffectively.

- Additional grants to voluntary organisations.

- The United Kingdom's White Paper was published at the end of March 2001, and represents a statement of policy intention similar to that of Sweden outlined above. It is the most comprehensive and important statement of policy intent since the last White Paper, Better Services for the Mentally Handicapped, published in 1971.

Amongst the many proposals are:

- Improved provision and funding to support mainstream schooling and transition from school to employment.
- Investment in advocacy services.
- A learning disability information centre and helpline.
- Various initiatives to improve access to mainstream health services.
- A commitment to achieve the closure of the remaining large mental handicap hospitals (long-stay institutions) by 2004, and action to improve access to ordinary housing.
- A five-year program to modernise day services, and improve access to adult education resources.
- The establishment of Learning Disability Partnership Boards at local authority level, to bring together all the statutory and voluntary services, with the active participation of people with learning difficulties and family members, to oversee the development of integrated services in pursuit of the objectives in the White Paper.
- The creation of a Learning Disability Task Force to advise the government on implementation, and an Implementation Support Team to promote change at regional and local level.

These aims and objectives are backed up with a range of specific targets, as well as funding for research. Detailed government guidance on implementation has yet to be produced.

Australia has its own disability strategy, which focuses on providing fair and equitable treatment to all citizens of the commonwealth[14]. The strategy is organized in terms of how it can be operationalized with respect to the four different roles of government organizations, which are outlined as follows:

1. Government as Provider

2. Government as Policy Advisor

3. Government as Purchaser

4. Government as Employer

Guidelines for each sector are outlined in a context which attempts to facilitate the full and equitable provision of services and supports to people with disabilities. Highlighted is the need to understand the current and changing needs of people with disabilities. Each sector must then develop services to meet these needs, and institute a vision of quality control while ensuring that choices are made which ensure the continuing viability of the organization to provide long-term policies, services and supports.

The Commonwealth Disability Strategy is a part of the Commonwealth-State Disability Agreement with the states of Australia. An example of a state strategy is contained with Victoria's State Draft DisAbility Plan[15], which is organized under three main goals:

1. Pursuing Individual Lifestyles

- Reorienting the Disability Support Plan
- Developing the Foundations of the Disability Support System
- Strengthening Protections and Safeguards

2. Building Inclusive Communities

- Strengthen the capacity of communities to be supportive and inclusive of people with a disability.
- Provide accessible and effective information to people with a disability on a range of disability supports and community services.

3. Making Public Services Accessible

- Promote employment opportunities for people with a disability.
- Promote improvements to inclusive education for people with a disability.
- Enhance access to public infrastructure (public transport, taxis and buildings).
- Enhance access to services that promote health and well-being.
- Monitor the extent to which people with a disability have equal opportunities to participate in the community.

---

1 Available for viewing at http://www.adapt.org/cesa/s1935bill.html .

2 The HCFA is a federal agency responsible for enforcing laws prohibiting discrimination on the basis of disability. Please refer to http://www.hcfa.gov/ .

3 http://www.rfv.se/english/stat/famba/tillf_k.htm

4 http://www.rfv.se/english/stat/famba/vardb_k.htm

5 http://www.rfv.se/english/stat/sick/ass_k.htm

6 http://www.kela.fi/pdfkirjasto/esite/guid2000.pdf

7 http://www.dss.gov.uk/lifeevent/benefits/disability_liv_allowance2.htm

8 http://www.dss.gov.uk/lifeevent/benefits/invalid_care_allowance.htm

9 S. Lingsom (1994). Payments for care: The case of Norway. In A. Evers, M. Pijl & C. Ungerson (Eds.), *Payments for care: A comparative overview*. Aldershot: Avebury.

10 http://www.facs.gov.au/disability/ood/CarerAllowFactSheet.htm

11 http://www.facs.gov.au/disability/ood/CarerPaymentFactSheet.htm

12 http://www.facs.gov.au/disability/ood/respite_march_2000.htm

13 http://alliance.unh.edu/section8finalrule.html

14 http://www.facs.gov.au/disability/cds/cds/cds_index.htm

15 http://www.dhs.vic.gov.au/disability

VI

Summary and Future Directions

The research identifies policy issues at the level of persons with disabilities, their families and their communities. It points to the need for policy actions at each of these levels.

The report shows that large numbers of people with disabilities are not receiving the supports they need to ensure their optimal health and development. From the initial identification of a disability, whether at birth or months or years later, inadequate supports, fragmented services, rigid institutions and negative attitudes compromise their health and well being and their ability to engage in their communities as active citizens.

For individuals, there is a need for more effective measures for identifying and coordinating their support requirements, program criteria that are responsive to individual needs, wider availability of personal supports which are affordable — even cost neutral — to individuals and yet fiscally sustainable for governments. Such supports would be delivered in ways that enable individuals to negotiate various transitions across the lifespan so they can live as independently as possible in the community as adults.

The research also found that, in many thousands of cases, informal providers are stretched beyond the limit. Lack of recognition of family members as essential workers in the disability support system results for many in low incomes and lack of benefits, vacations, sick leave and pensions. This puts them at an increased risk of falling ill or acquiring a disability themselves, and threatens the very backbone on which the disability support system has been built.

For families, there is a need for clear, practical recognition of the invaluable role they play in the disability support system. Such recognition would take the form of the financial assistance, support services, labour-market flexibility and other measures that will enable them to continue playing their vitally important role.

Communities are also hindered in their capacity to provide needed supports and services. Inadequate resourcing has led to a shortage of trained voluntary and paid

disability specialists, and to delays and gaps in the availability and delivery of much-needed specialised supports. Inaccessible community services and infrastructures compound the difficulties that individuals and families face, resulting in non-inclusive communities. Measures are needed to ensure the accessibility and inclusiveness of all mainstream services and programs. Investments and other measures are needed to ensure the availability of qualified people to meet the large and growing need for disability-specific support services that will enable people to live, learn, work and play in fully integrated rather than segregated situations.

To address the many issues facing individuals, families and communities, a coordinated and comprehensive policy response is needed. Such a response would draw from both collaborative and disentangled models of federalism:

- Collaborative among and within jurisdictions and sectors in the design of the policy strategy and its funding, monitoring and evaluation mechanisms, and for sharing information about lessons learned, innovation and success stories
- Disentangled as to the program measures used within jurisdictions to address the issues at hand to foster innovation and responsiveness

The policy response would take into account recent jurisprudence and human rights provisions, which make it clear that:

- The State has responsibility to address the historic disadvantage of persons with disabilities and is obligated to make investments to do so
- Disability supports should foster full participation, membership and inclusion of persons with disabilities
- Policies should build in means for persons with disabilities and their families to determine their needs and best interests and to have control over how these are best met. Mechanisms to secure individualized funding could be implemented as means of advancing personal identification of needs and best interests, and personal control in the meeting of those needs and interests.
- Independent/community living should be fostered and supported. The State has an obligation to shift from institutional to community housing options
- Policies must meet Charter and other human rights and respect the dignity and self-determination of the person.

Consistent with emerging trends in Canada and internationally, a leading-edge policy response would ideally:

- Shift from traditional approaches that frame individuals and families as "clients", to a more personalized, empowering, accountable and demand-driven approach in which individuals and families have better planning assistance and purchasing power to arrange for the supports that they deem appropriate
- Take full advantage of natural (i.e., informal) supports, while ensuring that those who provide informal support have the assistance they need to continue playing this role
- Invest in communities to assist local organisations to shift to more empowering and responsive modes of operation

Building on what has been learned internationally, an effective policy response for the Canadian context would:

- Be comprehensive, strategic and long-range, based on clear goals, measurable

outcomes and responsive indicators, to address the multitude of issues faced by individuals, families and communities

- Foster partnerships between governments for funding
- Engage the disability community in the policy process
- Shift from segregated, institutional modes of delivering disability supports to modes of delivery that foster inclusion and full participation

Key priorities for action are to:

- Increase the availability of affordable and responsive disability supports to individuals.
  - While it is problematic to make distinctions between people most in need, those needing more help with personal care (e.g., washing, grooming, dressing, eating) and moving about at home would seem to be particularly vulnerable (130,000 and 85,000 people respectively in 1991 — **Appendix Table 1**).
  - While there is large unmet need for hearing devices, the much smaller number of people needing oral or sign language interpreter services face substantial out-of-pocket costs to meet their communication requirements (**Appendix Table 2**).
  - The approximately 50,000 people needing wheelchairs and scooters (**Appendix Table 5**) face substantial out-of-pocket costs to meet their mobility needs. Modifications to personal homes to make them safe and accessible are also crucial for people with mobility impairments, or who are deaf, deafened or blind (**Appendix Table 7**).
  - Inaccessible community transportation and physically inaccessible places of work are major issues. However, even if the transportation was available and the places of work accessible, 80,000 people who are not employed need human support (e.g., readers, oral or sign language interpreters, job coaches, personal assistants) or technical aids in the workplace in order to integrate into the paid labour force (**Table 24**).
- Ensure that family members have the financial support (e.g., reimbursement for disability-specific out-of-pocket costs) and emotional/health assistance (e.g., through occasional respite) that they need to continue playing their vitally important role in providing information support.
- Strengthen the capacity of NGOs to provide responsive, affordable disability supports.
- Devise administrative measures to facilitate the portability of individuals' disability supports across life situations, communities and provinces/territories.
- Engage the disability community in the policy process and in tracking investments for disability supports and outcomes for individuals and families.
- Ensure that provinces and territories have the financial capacity to deliver on these priorities.

On a practical level, the policy response will face a number of challenges. There are the ever-present issues of fiscal sustainability and equity. What level of public financial support is appropriate to address the needs that individuals, families and communities face and to what extent should costs be privately borne?

There are also political challenges. The issues raised in the research require a multifaceted, coordinated policy and program response. If complete disentanglement is not likely to yield the sought-for results, what kind of new federal-provincial/territorial regime and inter-provincial/territorial regime is required to meet the challenge of ensuring comprehensiveness and coordination? Which level of government would be responsible and accountable for delivering on which of the measures needed?

At the same time, if there are challenges and difficulties to work through, there are also measures which could possibly be used in more innovative ways than has been the case to date. Such measures include a mix of refundable tax credits, direct transfers to individuals, families and communities, and the Employment Insurance, Child Tax Benefit and Canada Pension Plan systems. How can these measures be more effectively tapped to yield the sought-for results?

Entirely new programs may be needed to deal with issues such as lack of access to health and dental benefits among those who provide support to family members with disabilities and who are not adequately covered by employer-based or individual insurance plans. New grant and loan programs may also be needed to foster wider accessibility and inclusiveness of community programs, services and opportunities. A new human resource strategy may be needed to ensure the availability of skilled, committed people to meet the ever-growing demand for services in the disability sector.

A recent proposal by The Roeher Institute (Striking a New Balance, 2001b) lays out some detailed options for consideration. However these questions are answered, it is difficult to conceive of a more innovative and comprehensive approach to issues of disability support without significant financial support from the federal government to provincial/territorial governments. The latter are ultimately responsible for direct delivery of programs and services in many of the areas that need to be addressed, but have been dealing with issues of fiscal constraint for the better part of the past decade. At the same time, intergovernmental agreements concerning accountability and reinvestments will likely be needed to ensure that any fiscal transfers from the federal government will result in a net increase in the provision of disability-specific supports that fall within provincial/territorial jurisdiction. In other words, provincial/territorial investments are needed and could be furthered with federal assistance.

Through shared commitment to finding new solutions to the challenges at hand, both levels of government can work together where needed, and independently where appropriate, to move In Unison into action. In doing so they would be responding to the widespread desire among people with disabilities and their families to have the principles and commitments which underlay In Unison come to life.

---

1 35,000 of these people needed more help with personal care *and* more help moving about at home

Appendix

A. Note on the use of the GSS

The GSS is a complex data set that organises information according to whether it pertains to the "respondent" or the people involved in the life of the respondent (i.e., "roster members"). Typically, for analysis of respondent-level information, users of the data are urged by Statistics Canada to use the "Flag_1st", which filters for information that pertains to the respondent, who is always the first record in a given case. A given case may comprise several records (i.e., the respondent and people helped by, or who provide help to, the respondent).

However, owing to the file structure, certain detailed information (i.e., who the respondent helps with personal care because of the receiver's long-term health condition) may not be available on the first record of a given case. Use of the flag in those instances will result in under-counts. Conversely, by not using the flag, analysis yields over-counts in some instances as the weight variable may be counted more than once. This is because the respondent's weight is replicated across all records in a given case. Several records in a case may meet the criteria specified (e.g., respondent helps both mother and niece with personal care).

Where sought-for information was to be found not only on the first record in a given case, the following procedure was used:

- The data were filtered according to the parameters specified (e.g., any family members are helped by the respondent with personal care because of the family members' long term health conditions/disabilities). Data that did not meet the criteria were deleted. This captured the sought-for information that was in any of the records in a given case.
- The records were then Aggregated in SPSS, which was the statistical software package used. The software was instructed to compute the average weight of all records within a given case and to "Break" the data at each unique case. Only one record that met the criteria across any records in the case was retained (e.g., in case X, respondent helps one or more family members with personal care).

An output file with information that met the criteria across any of the records in the case was saved. A flag was derived to indicate that all the records in the file met the criteria specified. The file was then incorporated back into the master GSS file. The new variable was used in producing population counts and other statistical operations.

B. Tables

Appendix Table 1.

Extent of help needed for every day activities because of disability, showing numbers of people (HALS 1991)

	Helped - okay	Helped - more req'd.	Need help - none recv'd	Subtotals
Meal preparation	297,000	146,000	68,000	512,000
Grocery shopping	521,000	211,000	86,000	818,000
Ordinary housework	439,000	260,000	149,000	848,000
Heavy household chores	814,000	554,000	113,000	1,480,000
Personal finances	310,000	131,000	55,000	496,000
Personal care	156,000	79,000	51,000	285,000
Moving about at home	75,000	43,000	42,000	159,000

Appendix Table 2.

Number of persons using or needing aids/devices or svcs. for hearing (HALS 1991)

	Use	Need but do not have
Hearing aid w/T-Switch	119,000	42,000
Other hearing aid	185,000	87,000
Telecom. Device for the Deaf	28,000	9,000
Caption Decoder	16,000	10,000
Amplification system	32,000	17,000
Visual alarm	14,000	17,000
Computer to communicate	—	*5,000
Oral or sign language interpreter service	*4,000	*4,000
Message relay services	9,000	7,000
Volume control telephone	145,000	35,000
Other	9,000	21,000

*Small sample sizes. Use figures with caution.

Appendix Table 3.

Number of persons using or needing aids/devices or services for seeing (HALS 1991)

	Use	Need but do not have
Large print reading material	92,000	13,000
Braille reading material	5,000	—
Audio reading material	24,000	8,000
Reader	11,000	*3,000
Computer	6,000	*5,000
Glasses or contact lenses	295,000	19,000
Magnifier	129,000	9,000
Recording equipment	17,000	*3,000
White cane	23,000	*3,000
Guide dog	—	—
Other	8,000	*5,000
Total persons using/needing	337,000	45,000

*Small sample sizes. Use figures with caution.

Appendix Table 4.

Number of persons using or needing aids/devices for speaking (HALS 1991)

	Use	Need but do not have
Using any (artificial larynx, voice output aid, voice amplifier, computer to communicate, communications board such as Bliss, other)	11,000	10,000

Appendix Table 5.

Number of persons using or needing aids/devices for mobility (HALS 1991)

	Use	Need but do not have
Back or leg brace	87,000	18,000
Orthopaedic footwear	51,000	15,000
Artificial foot	*4,000	*3,000
Artificial leg	11,000	*5,000
Cane for walking	320,000	29,000
Crutches	54,000	7,000
Walker	86,000	16,000
Scooter	20,000	15,000
Manual wheelchair	106,000	16,000
Motorised wheelchair	22,000	18,000
Other aids	51,000	47,000
Not specified	176,000	178,000
Total persons using/needing	**526,000**	**140,000**

*Small sample sizes. Use figures with caution.

Appendix Table 6.

Number of persons using or needing aids/devices for agility (HALS 1991)

	Use	Need but do not have
Artificial hand	—	*3,000
Artificial arm	*4,000	*3,000
Arm brace	30,000	*5,000
Other for hands and arms	62,000	19,000
Total persons using/needing	**100,000**	**23,000**

* Small sample sizes. Use figures with caution.

Appendix Table 7.

Number of persons using or needing specialised features inside their residence (HALS 1991)

	Adults (15 years and older)		Children (younger than 15 years)	
	Use	Need but do not have	Use	Need but do not have
Grab bars	90,000	85,000	*1,000	3,000
Elevator or lift device	26,000	19,000	*1,000	2,000
Widened doorways or hallways	28,000	10,000	*1,000	2,000
Visual or flashing alarms	9,000	12,000	*1,000	*1,000
Audio warning devices	10,000	13,000	*1,000	2,600
Automatic or easy to open doors	29,000	14,000	*1,000	2,000
Lowered counters, sinks, switches	15,000	8,000	—	*1,000
Bed or bath lifts	16,000	23,000	2,000	2,000
Lever door handles	23,000	9,000	*1,000	*1,000
Emergency call system	23,000	23,000	—	*1,000
Other features	19,000	27,000	4,000	5,000
Total using/needing	**128,000**	**148,000**	**7,000**	**9,000**

* Small sample sizes. Use figures with caution.

Appendix Table 8.

Working-age persons with disabilities, help with everyday activities and key life situations

	Need no help	Helped - okay	Helped - more req'd
EMPLOYMENT AND FINANCIAL			
Employed	60.3%	33.8%	27.2%
Need one or more job accommodations	22.1%	49.7%	61.6%
Changed job because of condition	15.3%	27.6%	35.6%
Last worked 2 years ago or more, or never worked	25.6%	49.2%	51.5%
Had non-reimbursed expenses for disability	27.0%	40.3%	51.6%
Paid for help with everyday activities	—	15.5%	27.6%
Perceived employment discrimination because of condition	9.3%	14.9%	17.8%
Not in the Labour Force - Completely prevented from work because of disability	42.5%	76.9%	77.8%
Not in the Labour Force - Looked for work in past two years	20.1%	14.5%	11.0%
Not in the Labour Force - Will look for work in next 6 months	21.6%	14.9%	11.7%
Received disability pension/benefits	18.0%	46.9%	52.0%
Estimated personal income from all sources	$ 20,270	$ 15,616	$ 14,810
EDUCATION AND TRAINING			
Completed schooling beyond high school graduation	42.5%	34.2%	37.2%
Enrolled at school, college or university	14.7%	6.8%	7.6%
Reading and writing skills not adequate in daily life	8.2%	12.3%	16.0%
Low literacy and not plan to train to improve reading and writing skills	41.5%	67.3%	72.2%
Ever taken work-related training	38.7%	34.1%	34.2%
Who had disability before completing formal schooling:			
- choice of courses or career affected because of condition	29.1%	55.7%	64.3%
- began school later than most people because of condition	7.7%	14.4%	19.0%
- education was interrupted for long periods of time because of condition	19.3%	36.2%	37.2%
- changed schools because of condition	18.6%	23.1%	28.9%
- went back to school for re-training because of condition	18.6%	25.4%	28.5%
- changed course of studies because of condition	14.3%	23.3%	27.0%
- attended special school or special classes in regular school because of cond.	16.0%	23.1%	23.5%
- took fewer courses or subjects at school/college/univ because of cond.	14.6%	30.5%	34.0%
- took correspondence courses because of condition	9.9%	13.7%	17.9%
- left community to attend school because of condition	8.7%	12.4%	18.3%
GEOGRAPHIC MOBILITY			
Have moved (i.e., not in same dwelling as 5 years ago)	50.1%	49.1%	44.9%
Considers self restricted to personal residence	29.2%	43.9%	47.2%
Condition prevents taking long distance trips	7.5%	27.5%	34.1%
Have difficulty travelling by airplane	5.1%	11.2%	23.6%
Have difficulty taking long distance trips by train	3.6%	9.8%	26.3%
Have difficulty taking long distance trips by bus	3.4%	18.7%	22.7%
Have local transportation problems	3.8%	14.3%	19.6%
SOCIAL, AFFECT AND PERSONAL CONTROL			
Now divorced, separated or widowed (historical marital status)	13.9%	14.2%	18.8%
Often feel very lonely or remote from others	7.7%	12.4%	16.9%
Often feel depressed or very unhappy	6.9%	12.2%	16.2%
Feel not too happy about how things are these days	10.1%	17.1%	24.1%
Have trouble with pain or discomfort	40.0%	71.0%	71.8%
Of those with pain/discomfort, prevented from doing most activities	16.0%	40.5%	45.3%
Not much/no control in everyday decisions	2.5%	9.6%	13.5%
COMMUNITY AND SERVICE INVOLVEMENT			
Would like to be more active in leisure activities	38.0%	47.0%	52.7%
Not more active in leisure activities because need assistance from others	3.0%	13.8%	23.2%
Would like to be more physically active	47.0%	62.4%	66.6%
Had difficulty getting health or social services in past 3 months	4.3%	6.5%	8.3%

Appendix Table 9.

Randomly selected family members receiving help with everyday activities because of disability, including in-laws, showing numbers and percentages helped

	Number helped	Percentage helped
Spouse/partner (incl. ex-spouse or partner)	604,000	30.3%
Son/daughter (incl. son or daughter-in-law)	173,000	8.7%
Father/mother (incl. father or mother-in-law)	883,000	44.3%
Brother/sister (incl. brother or sister-in-law)	159,000	8.0%
Grandfather/grandmother	108,000	5.4%
Grandson/granddaughter	—	—
Uncle/aunt/cousin/nephew/niece	65,000	3.3%
Total	**1,993,000**	**100.0%**

Source: GSS Cycle 11, 1996, respondents who helped any family member by family member helped on the first records of cases

Appendix Table 10.

Impacts of helping on family members who need extra support in order to continue helping

	Family members who provide help who themselves need support	Number of family members who provide help who themselves need support	Per cent of those helping anyone because of disability	Per cent of those who do not help anyone because of disability
	Per cent	Number affected	Per cent	Per cent
Family members who provide help	54.3%	1,209,000		
- had employment income in year	76.1%	876,000	72.0%	67.9%
- worked at job/business last week	62.3%	749,000	58.2%	56.8%
- of those who did not work last week, worked at some point in the year	34.0%	154,000	29.0%	26.6%
- turned down a job offer as a result of helping	5.7%	69,000	4.6%	
- changed hours of work as a result of helping	22.3%	203,000	21.4%	
- came late to work or left work early as a result of helping	40.0%	361,000	30.4%	
- missed a day or more of work as a result of helping	38.1%	344,000	28.1%	
- job performance affected as a result of helping	20.1%	180,000	13.3%	
- postponed plans to enrol in education/training as a result of helping	8.5%	103,000	8.1%	
- had income from EI in year	12.2%	139,000	11.9%	9.9%
- had income from C/QPP in year	8.6%	98,000	13.9%	16.2%
- had income from social assistance/welfare	4.6%	53,000	5.7%	5.8%
- would find flexible work/study helpful	22.6%	274,000	12.3%	
- nearly always feel stressed helping and meeting other responsibilities	23.1%	278,000	16.8%	
- rate personal health as fair or poor	11.0%	131,000	10.9%	9.5%
- health affected as result of helping	35.5%	423,000	22.6%	
- have activity limitation (i.e., disability)	16.0%	191,000	15.9%	14.5%
- changed holiday plans as result of helping	37.8%	458,000	26.4%	
- feel extremely or quite a bit burdened in helping	8.6%	104,000	5.0%	
- sometimes or nearly always wish someone would take over helping	47.8%	575,000	34.6%	
- would find it helpful to have info on how to be effective provider of help	23.0%	278,000	12.8%	
- would find info on nature of condition helpful	25.7%	311,000	12.9%	
- would find counselling helpful	8.9%	108,000	5.3%	
- would find occasional relief helpful	30.8%	373,000	15.3%	
- would find something else helpful	16.3%	198,000	8.4%	
- had extra expenses as a result of helping	59.8%	719,000	43.4%	
- would find financial compensation helful	29.6%	359,000	17.1%	
	Averages		**Averages**	**Averages**
Personal income	$27,275		$26,160	$25,925
Household income	$49,425		$48,145	$47,610
Weeks worked per year	47		46	44
Hours worked per week	38		38	39
Weeks per year spouse worked	48		47	48
Hours per week spouse worked	42		42	40
Age at which became disabled	40		40	44

Appendix Table 11.

Sources of information people use to get various assistance to address disability-related needs (GSS, Cycle 11)

	Meal Preparation		House cleaning		House maintenance		Grocery shopping		Transportation		Banking / bill paying		Personal care	
RELATIVES	174,000	29.2%	213,000	24.8%	145,000	26.7%	196,000	32.0%	204,000	34.6%	146,000	36.0%	106,000	23.3%
ANY OTHERS	108,000	13.6%	267,000	31.0%	134,000	24.8%	88,000	14.4%	101,000	17.2%	31,000	7.7%	158,000	34.7%
NOTHING	314,000	52.7%	380,000	44.2%	263,000	48.5%	328,000	53.6%	284,000	48.2%	228,000	56.3%	191,000	42.0%
Total	596,000	100.0%	860,000	100.0%	542,000	100.0%	612,000	100.0%	589,000	100.0%	405,000	100.0%	455,000	100.0%

C. Discussion of Selected Trends

1. Jurisprudence On Disability Supports In Canada

Developing a comprehensive policy strategy to provide needed disability supports to persons with disabilities and their families should take account of the current legal obligations of governments, beyond statutory law and public policy. For this purpose, the research for this study included a review of primarily Canadian jurisprudence on the subject. A small sample of American cases was also examined because of the direct bearing the cases have on the rights of persons with disabilities, and because of the way in which their reasoning elaborates on that of comparable Canadian cases. The review devoted particular, but not exclusive, attention to case law where persons with disabilities have been directly involved. The focus of the review was on leading cases that deal with or otherwise define the legal rights of persons with disabilities, particularly the right to access needed support services.

Canadian courts have been especially fertile ground for the development of this kind of jurisprudence due to the inclusion of the Canadian Charter of Rights and Freedoms in the Canadian Constitution in 1982, and particularly with the coming into force of the Charter's section 15 equality rights in 1985. This section enshrined the equality rights of persons with mental and physical disabilities.

Section 15(1) of the Canadian Charter of Rights and Freedoms is fundamentally similar to the prohibitions of discrimination found in other human rights legislation in Canada and around the world. It reads as follows:

> *Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.*

For more than a decade, Canada remained the only nation in the world that specifically guaranteed the equality rights of persons with disabilities in its constitution. It was not until after that decade had passed that the first Canadian case involving the equality rights of persons with disabilities found its way to the Supreme Court of Canada.

Lens For Analysis

A lens of full membership, participation, and inclusion was used to guide the analysis of case law here, given the commitment to these principles articulated in In Unison. This approach is consistent with emerging trends in jurisprudence and disability. Donna Greschner, for instance, has proposed a model for determining the meaning of s. 15(1) of the Canadian Charter of Rights and Freedoms that she calls the "full membership" model. Mosoff and Grant speak of this model as "setting out a view of equality which highlights the importance of membership and participation in society's important institutions."

Jurisprudence dealing with equality and discrimination has focused on whether an act — or a failure to act — of a government agency or private facility leaves a member of a protected category, such as a person with a disability, worse off than if the act or failure had not occurred. In other words, the 'best interests' of the person

is the operating standard. However, adherence to the standard raises some questions as an adequate guide for state responsibility to meet disability support needs. For one, it can never be said that a 'best interests' test is a simple calculation. As well, the standard begs the question of who is best able to determine what are an individual's best interests.

For example, the disability advocacy community was extremely disappointed in the Supreme Court's Eaton decision. Inclusion was treated as a value not worthy of consideration within a narrow "best interests" analysis of Emily Eaton's experience in a regular classroom in her neighbourhood school — a school operated by her adversaries in the litigation, and which alone provided the evidence that such experience was overwhelmingly negative. Eaton happened to be the first case to come before the Supreme Court in which the equality claim of a person with a disability was directly at issue. Even though the case foundered on the question of what was in Emily Eaton's best interests, the Court was prepared to endorse the principle of inclusion as the "norm of general application because of the benefits it generally provides".

Subsequent cases, however, have begun to expand the importance of inclusion and the recognition of each person's right to belong as the underlying purpose of s. 15 of the Charter. The focus on "dignity" in Law and its successors is essentially an indictment of practices that serve to exclude persons traditionally regarded as less worthy of participation in the activities and benefits of a free and democratic society. As Mosoff and Grant have put it,

> *The advantage of the "full membership" model of equality is that it puts inclusion as the highest order value. . . . If this were followed through, . . . inclusion would inform both equality and best interests. Being the highest value, inclusion would be prima facie the best interests of all persons with disabilities. . . .*

These insights have always been present in the Supreme Court's treatment of s. 15 of the Charter. For example, from McIntyre J. in Andrews ("recognised at law as human beings"), through L'Heureux-Dubé J. in the 1995 trilogy ("members of Canadian society, equally deserving of concern, respect and consideration") to Iacobucci J. in Law and Binnie J. in Granovsky ("human dignity and freedom").

Summary of Findings

What do the cases reviewed for this research tell us about state obligations with respect to funding, regulation, provision and entitlement to disability-related support services?

a) Responsibility of the State Concerning Disadvantage

Recent jurisprudence (e.g. Law) places a discrimination complaint in its larger social, historical, political and legal context. Rather than a formalistic and mechanical approach, Iacobucci J. said in Law that the complaint must be positioned in the broader picture of government and societal action, and how they create or alleviate personal disadvantage. Binnie J. was no doubt following this precedent when he wrote in Granovsky that "The true focus of the s. 15(1) disability analysis is not on the impairment as such, . . . but is on the problematic responses of the state". He acknowledged that the state is responsible for many elements of "the economic and social environment" which is the context in which discrimination occurs.

b) "Best Interests"

The emphasis on the best interests of the person is a common thread running throughout the brief history we have examined. Unlawful discrimination is still identified as treatment that results in less advantage for a person or persons with a disability than for others. Although that is not the whole story, that part of the story is reliably true. This begs the question of what forms of support actually are in the person's best interests. The Supreme Court's prompt to this often vexing question is that the "legitimate feelings" of the individual are the primary test. This still leaves the question of what is "legitimate", which may involve expert opinion, both as to what is best for the person and what is best for the viability and effectiveness of the state's overall commitment to health and social services.

c) Freedom and Dignity

The most significant add-on to the "best interests" approach has been the re-focussing of the Supreme Court's vision on the "human freedom and dignity" purpose of s. 15 of the Charter. Clearly, institutional care ("unnecessary institutional confinement" as the U.S. Supreme Court describes it in Olmstead) is a violation of this standard. Any service system which provides only an isolated, partial life to those forced to depend on it is nothing more than a paradigm for discrimination on grounds of disability, from the perspectives of both best interests and human dignity.

The most recent disability/equality judgement from the Supreme Court of Canada, Granovsky, posits a test of whether the impugned law "promotes the view that equality claimants have diminished value in society", rather than a full-blown best-interests test in determining whether the law discriminates against a person with a disability. Any policy or legislation that enables the state to provide services that manage to avoid demeaning the recipients of that service in the eyes of the public, yet still fall far short of meeting their true needs, could be spared from an allegation of discrimination by such a standard. In contrast, the test set out by Ginsburg J. for the U.S. Supreme Court in Olmstead focuses strongly on the practical harms caused by a discriminatory system: impaired "family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment". It is difficult to imagine that the Supreme Court of Canada would not endorse these as valuable indicia of discrimination in the provision of support services. They are certainly not in conflict with the human dignity approach.

d) The Duty to Accommodate

The duty to accommodate individual needs has particular significance for persons with disabilities. There is no real accommodation without individualisation. Whether and when this principle will extend to individualised funding of support services remains to be seen. Funding, in and of itself, is no longer an obstacle to a complaint of discrimination under s. 15 of the Charter.

The notion of "undue hardship" is a difficult one to apply to Charter equality jurisprudence, because governments can rarely prove that they do not have sufficient resources to accommodate the needs of an individual claimant, or a small and discrete number of claimants. In Eldridge, it was estimated that the yearly cost of providing sign-language interpreters in health care settings in British Columbia would be no more than $150,000 a year. In Grismer, McLachlin J., as she then was,

warned against "putting too low a value on accommodating the disabled". The Nova Scotia Court of Appeal in Cameron, however, said that the government has the right to establish priorities in its health care budget.

In Schachter v. Canada, the principles outlined by Lamer C.J. were as follows:

> *This Court has held, and rightly so, that budgetary considerations cannot be used to justify a violation under s. 1. . . . Any remedy granted by a court will have some budgetary repercussions whether it be a saving of money or an expenditure of money. . . . The question is not whether courts can make decisions that impact on budgetary policy; it is to what degree they can appropriately do so. A remedy which entails an intrusion into this sphere so substantial as to change the nature of the legislative scheme in question is clearly inappropriate.*

Maintaining the viability and fairness of the service system across the province or across the country, though, is also likely to be high on the courts' agendas. The courts will need a great deal of assistance from government and from persons with disabilities, their families and their advocates to work out the fairest possible balance.

e) Addressing Needs with Finite Resources

The approach to allocating state resources would seem to be best guided by the Supreme Court's recent human dignity emphasis in its judgements on equality. This approach would give persons with disabilities the dignity of self-determination in the area of support services. It would also maximise the attainment of their self-identified 'best interests' and their human dignity and value. This person-centred approach must be balanced against the larger picture of service needs within the jurisdiction where a person with a disability lives. The courts have recognised that the state has the greatest obligation to serve those with the greatest needs, even to the point of decreasing the level of service for those whose needs, though real, are not as great.

f) Summary of Principles

Several key principles can be distilled and synthesized from the jurisprudence to guide the design and implementation of a policy strategy for disability supports. First, disability supports, by their nature and definition, should foster full participation, membership, and inclusion. Second, people with disabilities have long been disadvantaged and the state has a responsibility to address that disadvantage with an investment that should not put "too low a value on accommodating the disabled." Third, human dignity and self-determination should be protected in policy – through investments and provisions that assign to people and their families maximum control over how their supports will be provided, and to define for themselves how their own 'best interests' will be met. Fourth, as the state is to safeguard human dignity and self-determination, people have a right to live in the community and the state has a responsibility to support the shift from institutional care to community life. Fifth, managing investments in disability supports should ensure that Charter rights to equality are met, and that disparities in level of and access to supports – across communities, and provinces/territories – are addressed, understanding that the state may not be able to meet all needs for support.

The Traditional Service Delivery System

The traditional service delivery system for people with disabilities in Canada has many features that are typically seen across various types of disabilities, and across communities:

- delivery of services is usually done through transfer payment agencies
- funds are available only to agencies and not directly to persons
- many services are provided in congregate settings, rather than being personalised
- supports tend to be professionally driven, and persons with disabilities and their families play a minor role in planning and directing their supports
- the focus of many community services is rehabilitation oriented and institutional services play a major role in people's lives
- services are designed to "help" rather than being designed to build capacity of the person, their family and the community
- services are usually poorly co-ordinated
- the focus of supports is generally on practical supports rather than on facilitation of social inclusion in community
- institutionalised and segregated options are a feature of the service system.

An Emerging Paradigm of Disability and Community

An emerging paradigm of disability and community reflects significant changes in the traditional service delivery system. Paradigms of disability and community have emerged in theory and practice in the last twenty years. They can be seen in a patchwork approach to innovation across the country. Policy and practice are beginning to reflect the new paradigm, and research is showing very positive outcomes for people with disabilities. The features of the emerging paradigm are consistent with the principles articulated in In Unison and include:

- control and choice by people with disabilities and their families in the way their disability supports are provided
- personalised planning, support, and funding, designed to facilitate natural, informal support (family and friends) and to build citizenship opportunities
- a focus on personal relationships, participation in the community, and opportunities to contribute. These domains are critical to reducing the vulnerability of people with disabilities and to safeguarding quality of life.
- planning and support include both formal and informal support. Formal support is paid support, with the person and their network determining whom they will hire. Informal support includes family, friends and others within the person's network.
- funding dedicated to persons with disabilities and/or their family over which they have and/or designate their choice about how the money is to be administered. Funding moves with the person; people with disabilities live and work where they choose.
- planning for the individual is unencumbered, and kept separate from service

provision. Infrastructures, such as facilitators, are in place to assist persons and their networks to plan and access their disability supports.

Shifting to a more empowering and capacity-building community supports and service system requires addressing a number of transitional issues. These include shifting to a demand-driven system, accelerating deinstitutionalisation, investing in community-capacity building and sharing information and experience.

Shifting to a demand-driven system

Most of the public resources directed to disability supports are allocated through a "supply-side" approach. Governments fund agencies to deliver supports to people with disabilities and their families who then must approach individual service agencies, each of which often has its own eligibility criteria – as discussed in the section of this report on policy issues. This supply-side approach cannot be as responsive to the diversity of need as it should be.

A 'demand-driven' alternative provides financial resources directly to persons and families to purchase the supports most appropriate and responsive to their needs. The research has shown this approach to be effective in fostering fuller inclusion of people and families in community life. If this approach were more fully available across the country, it would promote greater equity among persons dependent on disability-related supplies and services, would improve portability of supports, and would strengthen accountability to persons and families.

Individualised funding initiatives exist in most provinces and territories, but generally there is more practice than policy. Mechanisms are being developed for those who want the control that individualised funding brings, without the administrative responsibilities. Labour issues need to be more effectively dealt with so that increased choice and portability in supports can still meet labour's concerns for fair working conditions and job security.

Accelerating deinstitutionalisation

Deinstitutionalisation reform requires new financing. Progress in deinstitutionalisation is slowing down in Canada, and in some provinces there is retreat. Additional investments are required in transitional funding so that facilities can downsize and close, while persons and families and communities obtain the financial resources for enhanced community supports. A financing arrangement is needed that recognises that some provinces and communities have long been under funded in the development of community supports for people with disabilities. Some targeted funds to poorer provinces may be needed to assist in the deinstitutionalisation effort.

Community Capacity Building

Significant innovations are in evidence in many communities. They include:

- Individualised funding;
- Introduction of independent planning and advocacy supports to persons and families. These should improve accountability and lead to more personalised supports;

- Moving from sheltered work to more personalised and inclusive training and employment;
- Supported independent/ personalised living arrangements, in addition to group homes;
- Employability programs for those with the most challenging disabilities and most exclusion from the labour market.

Some community-based reform efforts are reaching limits, in part because of a lack of transition funding. For example, a community-wide effort in Thunder Bay, Ontario was launched in the early 1990s to shift from the block-funded agency system, characterised by a highly unionised labour force, to a personalised system where fewer group living arrangements and sheltered facilities would be utilised. The shift required a scale of change similar to that of closing a major institution with the attendant financial pressures. However, as a project evaluation study indicated, without some transition dollars like those arranged for the national deinstitutionalisation initiative in the 1990s, the shift would be difficult to make. As with closing an institution, both old and the new support systems — agency-funded and individually-funded, in this case — needed to be funded simultaneously for a limited period. Many communities will require transition funds to shift to a more empowering community supports system and to address the range of human resource issues likely to be encountered along the way.

Information Exchange

Shifting from traditional to more empowering community supports systems will take place in a multitude of ways. Many different models and options should be encouraged. Communities can learn from one another through a more comprehensive and co-ordinated system for sharing information across communities and jurisdictions on best practices, innovations, change strategies, and investment/financing tools.

References

Armstrong, P. & Kits, O. (2001). *One Hundred Years of Caregiving.* Prepared for the Law Commission of Canada.

Arno, P.S., Levine, C. & Memmot, M.M. (1999). The economic value of informal caregiving. *Health Affairs,* 18 (2), 148-152.

BC Ministry of Advanced Education (2000). *Labour force statistics – November 2000.* Available: http://www.aett.gov.bc.ca/labourmarketinfo/lfsurvey/nov00/nov00.htm

Barris, T. (1998). The caregivers. *CARP News.* Available: www.caregiver.on.ca/nwkhcn.html

Canadian Association of Family Resource Programs (2000). *Family support: A national priority – A response to the public report "Public dialogue on the National Children's Agenda: Developing a shared vision."* Ottawa: Canadian Association of Family Resource Programs.

Council of Canadians with Disabilities (November 1999). *A National Strategy For Persons With Disabilities: The Community Definition.* Winnipeg: Council of Canadians with Disabilities.

Dye, T. R. (1995). *Understanding Public Policy (Eighth Ed).* Englewood Cliffs, NJ: Prentice-Hall.

Human Resources Development Canada, Income Security and Social Development, Applied Research Branch (January 14, 2000). "Findings from Consultations on the Health and Activity Limitation Survey 2001". Ottawa: Applied Research Branch.

Irwin, S.H. & Lero, D. (1997). *In Our Way: Child Care Barriers to Full Workforce Participation Experienced by Parents of Children with Special Needs and Potential Remedies.* Wreck Cove, Nova Scotia: Breton Books.

Jacobs, E. & McDermott, S. (1989). "Family Caregiver Costs of Chronically Ill and Handicapped Children: Method and Literature Review". *Public Health Reports, 104,* 158-163.

Kagan, J. (2000). *Lifespan Respite.* Annandale, VA: National Respite Coalition.

Lazar, H. (1998). "The federal role in a new social union: Ottawa at a crossroads". In Canada: the state of the federation 1997, Non-constitutional renewal. Kingston : Queens University Press.

Lingsom, S. (1994). *Payments for care: The case of Norway.* In A. Evers, M. Pijl & C. Ungerson (Eds.), Payments for care: A comparative overview. Aldershot: Avebury.

Lukemeyer, A., Meyers, M.K. & Smeeding, T. (2000). Expensive Children in Poor Families: Out-of-pocket Expenditures for the Care of Disabled and Chronically Ill Children in Welfare Families. *Journal of Marriage and the Family, 62 (2),* 399.

Metropolitan Life Insurance Company (1999). *The MetLife Juggling Act Study: Balancing Caregiving with Work and the Costs Involved.* New York: Metropolitan Life Insurance Company.

Montgomery, R.J.V. & Kosloski, K.D. (2000). Family Caregiving: Change, Continuity and Diversity. In P. Lawton & R. Rubenstein (Eds.), *Interventions in dementia care.* New York: Springer Publishing Company.

National Council on Welfare (Autumn 2000). *Welfare Incomes 1999.* Ottawa: National Council on Welfare.

Ontario Roundtable on Individualized Funding (2000). *Linking individualized supports and direct funding: Making money work for people.* Toronto: Individualized Funding Coalition for Ontario.

Roeher Institute (1996). *Building Bridges: Inclusive Post- Secondary Education for People with Intellectual Disabilities.* North York, ON: The Roeher Institute.

Roeher Institute (March 1997). Final Evaluation Report, Self-Managed Attendant Services in Ontario: Direct Funding Pilot Project, Toronto: Centre for Independent Living — Toronto.

Roeher Institute (1998). *Disability-Status Transitions and Labour-Force Activity Transitions of Persons with Disabilities: An Analysis Based on the Survey of Labour and Income Dynamics (1993 and 1994).* Ottawa: Human Resources Development Canada, Income Security and Social Development, Applied Research Branch.

Roeher Institute (2000a) *Count us In! A Demographic Overview of Childhood and Disability.* Toronto: The Roeher Institute.

Roeher Institute (2000b). *Finding a way in: Parents on social assistance caring for children with disabilities.* Toronto: The Roeher Institute.

Roeher Institute (2001a, unpublished)."Children with Disabilities and their Families: Demographics and policy issues". Toronto: The Roeher Institute.

Roeher Institute (2001b). *Striking a New Balance: Proposal for a Joint Federal-Provincial/Territorial Disability Supports Investment Initiative.* Toronto: The Roeher Institute.

SFS (1993). Swedish code of statutes SFS 1993: 387 — *Act concerning support and service for persons with certain functional impairments.* Available: http://www.independentliving.org/docs3/englss.html

Statistics Canada (1994). *Selected Characteristics of Persons with Disabilities Residing in Households — 1991 Health and Activity Limitation Survey.* Ottawa: Minister of Industry, Science and Technology.

Statistics Canada, 1996 Census Nation tables, *Census families in private households by selected household and dwelling characteristics, 1996 Census.* Available: http://www.statcan.ca/english/Pgdb/People/Families/famil64a.htm

Statistics Canada. Table 326-0002 — Consumer price index (CPI), 1996 basket content, annual. Available: http://cansim2.statcan.ca/cgiwin/cnsmcgi.exe?Lang=E&RootDir=CII/&ResultTemplate=CII/CII_pick&Array_Pick=1&ArrayId=3260002

Statistics Canada (2000). *Women in Canada 2000.* Ottawa: Ministry of Industry.

Torjman, S. (2000). *Proposal for a National Personal Supports Fund.* Ottawa: The Caledon Institute of Social Policy.

Townson, M. & Canadian Advisory Council on the Status of Women (1995). *Women's Financial Futures: Mid-Life Prospects for a Secure Retirement.* Ottawa: Canadian Advisory Council on the Status of Women.

Walt, G. (1994). *Health policy: An introduction to process and power.* Johannesburg: Witwatersrand University Press.

http://www.adapt.org/casa/s1935bill.html .
http://alliance.unh.edu/section8finalrule.html .
http://www.dss.gov.uk/lifeevent/benefits/invalid_care_allowance.htm
http://www.dss.gov.uk/lifeevent/benefits/disability_liv_allowance2.htm
http://www.dhs.vic.gov.au/disability
http://www.facs.gov.au/disability/ood/CarerAllowFactSheet.htm
http://www.facs.gov.au/disability/ood/CarerPaymentFactSheet.htm
http://www.facs.gov.au/disability/ood/respite_march_2000.htm
http://www.facs.gov.au/disability/cds/cds/cds_index.htm
http://www.hcfa.gov/
http://www.kela.fi/pdfkirjasto/esite/guid2000.pdf

http://www.rfv.se/english/stat/famba/tillf_k.htm
http://www.rfv.se/english/stat/famba/vardb_k.htm
http://www.rfv.se/english/stat/sick/ass_k.htm